



Save the Children

I AM LIKE YOU

An investigation into the position of children with disabilities
in Albania

A Consultancy Report

for

“Save the Children, Albania Programme”

Alison Closs MA MEd (SEN)
Senior Lecturer/Researcher
in Equity Studies & Special Education
Department of Educational Studies
Moray House Institute of Education
University of Edinburgh
Holyrood Road
Edinburgh EH8 8AQ

Tel. (work~direct line): 00 44 131 651 6443

Tel. & Fax. (home): 00 44 131 667 2086

Email alison.closs@ed.ac.uk

Virxhil Nano PhD (Spec. Psych.)
Assistant Professor and
Head of Qualifications Department
Institute of Pedagogical Research
Rr. Naim Frasheri, 37
Tirana
Albania

Tel./Fax 00 355 4 256 441

Email virxhil_nano@yahoo.com

Estevan Ikonomi, MPA:
Programme Coordinator, Disability
Save the Children,
Rr. "Komuna e Parisit", L. 8, P. 1 Maji,
Vila "Lami"
P.O. Box 8185
Tirana, Albania

Tel. +355 4 261840, 261929, 266227

Fax: +355 4 263428

Email: estevanikonomi@savealbania.org

April 2003
(edited in March 2005)

Acknowledgements

We would like to thank warmly all the very many people who received our research team in visits or responded to our numerous questions in other ways. They included personnel from Government Ministries, Governmental and Non-Governmental Organisations, individual professional people with an interest in disability, including some with disabilities, and – above all – children and young people with disabilities and their families. They were unfailingly courteous and patient despite their own busy lives and multiple responsibilities. We hope that they feel that we have done justice to their views and that the report will be a positive contribution to improving the position of children with disabilities within Albanian society.

The title of our report is an extract from a statement made to us during our research by a boy with physical and mental disabilities. He had been mocked in the street about his appearance and wanted to protest to the other children that they should not tease him because, 'I am like you' (see Section 2 of the report for his full statement). We also believe that children with disabilities are *children* first, with very much in common with all other children, and we share this boy's feelings of frustration that this commonality and all children's equal value and rights are not always recognised in the positive ways that they should be.

The photographs on our inner title page are of Eduard and Zhuliana in the midst of their families. They are now young adults, who have been fortunate enough to spend their childhood in families who love them and who work hard to ensure the best life possible for them. We are grateful to them and their families for allowing us to use their photographs.

We have deliberately not included an executive summary. Readers who cannot afford sufficient time to read the report in its entirety should read the collated recommendations at the end of the report to realise the extent of work still to be undertaken for Albania's children with disabilities.

Finally we must issue the usual disclaimer, that this report records the findings and interpretations of the researchers themselves. It does not necessarily reflect the position of *Save the Children (Albania)*, which funded the research, and the publication of the report.

**Alison Closs
Virxhil Nano
Estevan Ikonomi**

April 2003

I Am Like You

An investigation into the position of children with disabilities
in Albania

A Consultancy Report
for
"Save the Children, Albania Programme"

by

Alison Closs and Virxhil Nano
with Estevan Ikonomi

Index of contents

1. [Introduction](#)
2. [Albanian society and disability](#)
3. [Ethnic and linguistic minority issues](#)
4. [The Albanian Government and disabled children](#)
5. [The role of Non-Governmental Organisations](#)
6. [Efficient cover of work to be done: gaps and 'overlap' in activities and roles](#)
7. [Numbers of children with disabilities and data collection](#)
8. ['Invisible' children](#)
9. [Families of children with disabilities](#)
10. [Siblings](#)
11. [After childhood – adult occupation and care](#)
12. [Financial support for families](#)
13. [Social services and social support at critical times](#)
14. [Residential Development Centres & Day Centres](#)
15. [Education](#)
16. [Inclusive schools](#)
17. [Special classes and schools](#)
18. [Educational early intervention](#)
19. [Health services](#)
20. [Professional roles and training](#)

[Conclusions](#)

[Collated Recommendations](#)

[References / Bibliography](#)

[Appendix 1: The research team, research methodology and organisation of the report](#)

[Appendix 2: Visits and meetings undertaken by the research team](#)

[Appendix 3: Tables of Governmental Institutions with numbers of pupils special schools and Classes\), residents \(Residential Development Centres and State Orphanages\) and clients \(Day Centres\) with disabilities](#)

[Appendix 4: Questionnaire for NGOs](#)

[Appendix 5: List of Acronyms in English and Albanian](#)

'I Am Like You'

An investigation into the position of children with disabilities in Albania

“We saw that he had become suddenly dangerously ill. I carried him wrapped in blankets during the night across the hills for six hours to reach help. In the hospital they wanted to take fluid from his spine but I wouldn’t allow it at first because I thought the big needle could kill or paralyse him. Maybe I was wrong in that, but they gave him antibiotics anyway – we had to pay for these. It was meningitis. He had a high temperature for twenty days and was in a deep coma. Some people said it was the evil eye but I didn’t believe that, it was God or the temperature from his illness. Then he began to recover very, very slowly, first he moved his limbs a little then eventually he became conscious. Later we realised that he was deaf. He did not learn to talk and maybe he is not completely all right in other ways. We took him to a holy place . . . who knows?”

“We decided to leave the village for the sake of our children (they have two other children) – we were so isolated and we wanted a better life for them but it is hard here in Tirana, very hard. Well, there’s no real work, just what you can do from time to time, housing isn’t good, but the (extended) family sometimes helps. I hadn’t heard before about this school (school for deaf children) but when we came to Tirana we heard about it and I brought him here - they have been good to us. I am happy for him to be here with other deaf children, but I really want him to be normal. I used to hope for a cure, but now, well . . . My son uses signs and I can’t understand him although my wife does a little because she learned in the school. The other two (children) feel frustrated too but sometimes they all play and laugh together. Sometimes he is very unreasonable and loses his temper when we can’t understand something he wants, and then I get angry too. But he is small and I am large, so I must try to be patient. The future? Well, he is still a small boy. He likes technical things like computers. There will probably be more worries about him later. We can only stay here and hope, although we miss our village. But you cannot live in distant places and have a child with problems. Help is only in the centre, here in Tirana.”

(Father of a boy aged 8 who had meningitis at nine months old and became deaf – see Section 2 of this report)

Section 1: Introduction

“Save the Children” commissioned us as a team of three people to undertake a widespread and intensive investigation into the current situation of children with disabilities in Albania. It involved visits to Ministries, GOs and NGOs and Associations of various kinds, primarily for discussions with key personnel but also, where practicable, to see services in action, speak with personnel at other levels and with service users. We participated in a number of meetings with parents’ associations and met families within their own homes across Albania, speaking with children and young adults with disabilities, their parents and siblings. Only the far north-east of the country and the extreme southern coast were not covered although both Albanian team members were aware to some extent of the situation of children with disabilities in these more distant areas. The research took place mainly throughout February 2003 but some follow-up meetings and discussions took place during March conducted by the Albanian members of the team.

We also drew on relevant publications from previous investigations and on NGO and other reports (see References at the end of the report). We have used these with caution as some are possibly out of date in a fast changing area of work, although only a few years old. Occasionally we have questioned some of their findings or conclusions and would hope that our own work would also be scrutinised critically! Our research was largely qualitative rather than quantitative although we provide lists of GOs and current numbers of their pupils/clients. (See Appendix 1 for a more detailed account of the research team, the process of the research, including methodology and data analysis, and of the structure of the report, Appendix 2 for a list of meetings, and Appendix 3 for tables of GOs' locations and numbers of pupils/clients/residents.)

We were asked to write an informative report outlining the situation of disabled children, giving recommendations for action by Government and Non-Government agencies, suggesting funding priorities for donors and identifying some projects appropriate for Save the Children itself to undertake in Albania. Recommendations are included in the text and then collated and in some cases elaborated, Section by Section, at the end of the report. An asterisk precedes recommendations that we believe should be prioritised.

We were also asked to advocate on behalf of children with disabilities, where possible using case studies and the views of children with disabilities themselves and their parents. We consider this to be of the utmost importance, as we do placing their views alongside those of policy makers and professionals. It is only by increasing *mutual* understanding and respect for the experience and expertise of others that partnership develops and collaboration can be really effective. A common finding internationally is that parents’ own knowledge and ‘expertise’ about their own children is often not acknowledged or used sufficiently by professionals.

We took Article 23 and the first part of Article 24 of the UN Convention on the Rights of the Child (UNICEF 1989) as the baseline for our investigation:

Article 23

1. States Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.
2. States Parties recognise the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognising the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development
4. States Parties shall promote, in the spirit of international co-operation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

Article 24

1. States Parties recognise the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

It is important to recognise that the Convention does not have a hierarchy of children to whom such rights should be accorded; they are for *all* children, without exception.

For the purposes of this report we have taken ‘children with disabilities’ to mean children with mental, physical or sensory impairments and those with serious, chronic or progressive medical conditions, that impact to a significant degree on their capacity to participate in the day-to-day activities participated in by their non-disabled peers.

Definitions are always surrounded by grey areas of uncertainty, but this definition also corresponds to the definition used in the *Normative Dispositions* of the recent Albanian legislation about the educational inclusion of ‘children with special needs’ (Albanian Government 2002a). It does not include children with social, emotional and behavioural difficulties unless such difficulties co-exist with disabilities, as they sometimes do. We did, however, have some limited discussions that referred to children with such difficulties and mention them in the report. We believe that a separate investigation focussing on them and on their experiences would be useful (Recommendation 1).

We have deliberately chosen to use the phrase ‘children with disabilities’ rather than ‘disabled children’ as we hope that it will remind us and those that read our report that *every one of these children is firstly a child*, with every child’s rights, and *never ‘just’ a child with disabilities*. A child with disabilities is also a child with abilities, with particular preferences, with personal charm for those close to him or her, and with the capacity to generate love in others. He or she is *always* a child with individuality, with the potential for some development, and with the need to be valued and loved by others.

Section 2: Albanian society and disability

The account of the Albanian father of his deaf young son's life that prefaced our report on Page 1 encapsulates many of the features of Albanian life and society today that can combine to make the lives of families with disabled children very difficult indeed. They include; poverty, isolation, lack of roads and transport, distance from medical help, cost of essential medication, superstition, internal migration to the city, poor housing, unemployment, lack of advice and information, lack of shared understanding, and the centralisation of resources in Tirana. However, it also illustrates some of the positive features of Albanian life and society that are vitally important to the lives of disabled children and that need to be supported by Government and by Albanian society. These include: family solidarity and support, love for children, stoicism and optimism against the odds, the existence of some resources and specialist staff who, although over-stretched, find the time, energy and commitment to respond constructively to children and their families.

The mark of a civilised society is sometimes said to be how it values and looks after its most vulnerable members. Albania was an early signatory to the UN Convention on the Rights of the Child and the country is therefore committed to developing the well-being of *all* its children (see Section 4 of the report for further reference to this). Children with disabilities are a minority within the child population numerically but are all individually of equal value with their non-disabled peers. It is important therefore that, as Albania develops, children with disabilities and their families benefit from progress on all fronts, equally and as of right with others, and that they are enabled to participate fully in Albanian society. This will only be possible if relevant Government Ministries, Governmental and Non-Governmental Organisations and the wider community of Albanian people, including disabled people and their families, collaborate now and in the future. Disability is at an intersection where resources managed by Health, Social Services, Education and NGOs, Housing and Transport can *all* make a contribution to the quality of life of children with disabilities. The contribution of one may be wasted where the contribution of another is either missing or in some way negates or confuses another.

There is clear evidence of positive motivation and of considerable thought, energy and goodwill in many areas of existing services in Albania today and on the part of many individuals involved. Some good work has already been accomplished but there are very substantial problems and areas requiring development before the position of children with disabilities can be seen as acceptable. Albanian officials and agencies generally acknowledge this state of affairs and there is no sense of complacency. The most evident emotion is frustration that work cannot proceed faster because of shortage of relevant resources; financial, material and personnel. There is always a risk that this frustration can become lethargy and despondency if the period of transition into an improved economy is too extended - there were some signs of this. We have not lost sight of ideals in our report but we have tried to temper our recommendations and suggestions with some pragmatism in the light of current constraints while including some longer-term and more ambitious recommendations to ensure that planners look further ahead than the immediate future.

People with disabilities are particularly vulnerable at transitional times when those that might be helpful become absorbed in their own particular difficulties. There is ample evidence of poverty, of internal and external migration, inadequate, relatively expensive and sometimes unavailable public utilities such as electricity and proper sanitation, crowded and inadequate public transport. The link between poverty and disability is inescapable.

Most of their families are poor, really poor, they don't eat well, they are not looked after well, they just don't get the attention that children with mental disabilities need.

(Educator in Day Centre)

They said to bring him down to the town to get the Social Benefit (financial support for disability). How could I get him there? There's no bus and I can't even move him in the house.
(Mother of 15 year old physically and mentally disabled boy)

They have no facilities as far as I can see, certainly no running water, so no washing machine. They can't afford disposable nappies. But they do care for him in these difficult circumstances. They have to buy his medicine and they do that somehow.
(NGO Representative about a migrant family with a doubly incontinent epileptic son)

The dominance and still growing size of Tirana and the relative underdevelopment of other towns and rural areas, especially in the north and inland south, ensure a grossly uneven distribution of services with Tirana being the location of the overwhelming majority of these. Tirana has the largest children's hospital and body of specialist medical experience, the two national medical and therapeutic centres for children with developmental and mental health problems. Tirana and nearby Durrës have four of the eight special schools including the only schools for deaf and for blind children, to name six critical resources for children with disabilities. With road and transport infrastructures still requiring development to many areas of the country, most distant or even relatively near families dread having to travel to Tirana to access these services. For some the obstacles are insurmountable. While the security of village or small town life with extended family networks has benefits, however hard the life, other families migrate to be where their children's special needs may best be met.

It wasn't really a choice, she needed to see the specialist often, she was at school here and she wanted us near, so we moved - the other two and my husband and me. We sold everything and came here. Do we like it? No, not really, we live poorly, but it's better for her.
Mother of blind girl (14)

One of the national trends is towards smaller family size. This is linked generally with lowered infant mortality and improved female education and health, all positive factors. However, one of the main helping resources in caring for more vulnerable people, whether elderly, sick, or our focused group of children with disabilities, is the extended family. The trend towards smaller families and the trends of internal migration and of continuing emigration of the young and well educated are all worrying. However strong the bonds of Albanian family life are, there is a likelihood that these trends may weaken the extended family in the coming years. Families, whether of three or four generations and extended, or of small two generation families, will require very practical and financial support on a national scale. Research on public attitudes to disability notes that social care institutions, *i.e.*, Governmental and Non-Governmental Organisations (GOs and NGOs), have come to be seen as necessary extensions of care to smaller families with disabled members (Albanian Disability Rights Foundation – ADRF 1998: 26). We believe that the Government should be considering *now* further practical and financial means to supporting families with disabled children. It is necessary to ensure that caring for children within the family continues to be the first choice of families and that it does not place an unreasonable burden upon family life. Such measures could include; increased financial support, priority for adequate housing and sanitation, loans for essential equipment such as washing machines where children are incontinent, entitlement to an annual quota of respite care, free travel vouchers for use in travelling with their children to essential services and meetings such as hospital appointments and attending school or day centres, if need be by taxi. (Recommendation 2).

Is Albania now a country that values diversity in the form of disability, that is socially inclusive? The ADRF survey mentioned above, published five years ago, records a complex picture. There seemed to be a general view among the public that people with disabilities are a 'neglected' sector of the population but that they are also worthy of respect and equity, at least within the family. Responses, however, became more ambivalent when different age and home location samples of the public were questioned in relation to the possibility of friendship and closer proximity of people with disabilities. It was clear then that there were limits to acceptance and that young adults – who had been most positive

about equity at home - and people who lived in Tirana were particularly negative about such prospects. The ADRF survey suggests that Tirana has become 'a noisy and chaotic metropolis that has no time to deal with the persons with disabilities' (Page 43). Certainly, it would seem, superficially, that more rural and stable areas offered better opportunities for developing closer contacts, but this may be a simplistic assumption.

Yes, I think he is accepted, because I am proud of him and love him and we go out together. I am confident enough to do this but it isn't like that for everyone. Many children with disabilities are hidden, especially those with severe and complex disabilities. Mental disability, mental health problems, they can be a taboo in villages and small towns.

(Mother and NGO Representative in small town)

They would stare and pass comments, sometimes quite loudly, and they would never smile at her or touch her as people normally would with other children. I wanted to shout at them and to cry at the same time.

(The mother of a girl with Down's syndrome explaining how she felt when she took her daughter for a walk in the park as a child)

I stay at home and do not work so that I can keep him company. He would not survive on the street here. Our society is still cruel in many ways.

(Mother of boy with physical and mental disabilities in northern town)

*But there are many people who have not been nice to me, especially in the street, "Eeeee! Look at him! What's wrong with him? He's mad - I don't want to look at him!" I feel angry and wish I were stronger then I would say to them, "Why are you doing that? It's not right, **I am like you**".*

(Boy with physical and medical disabilities and facial abnormality)

The ADRF survey did not sample the views of people with disabilities and their families. Our interviews found that, although families often acknowledged understanding and social inclusion within their families and among close friends, they found Albanian society generally unwelcoming to children with disabilities although they thought there had been some improvement in services for them.

I love my child, we all love our children - that is not the problem - the problem is having to fight for everything they need and the feeling that somehow they are not appreciated. It is better than it used to be perhaps, but change is slow in coming for everything in Albania, too slow.'

(Father of an 11 year old boy with profound mental and physical disabilities)

Life is definitely better now with the Centre but that was by our parents' own efforts, not by the efforts of the Government.

(Mother of girl (14) with severe learning difficulties)

On a more positive note, in research undertaken into a programme of inclusion of pupils with mild disabilities into mainstream schools (ADRF - Nano 2002:57), it was evident that the non-disabled pupils did not view their disabled peers as a problem within the class. Indeed, 66% of them felt that they had learned from the experience of inclusion. However, issues about friendship between pupils with and without disability and about a positive welcome from them were not explored in this research.

However, it is plainly important to develop *both* private intellectual and emotional acceptance of disability *and* actual behaviour that reflects more fully positive inner inclusive intentions. Sadly, there is often a gap between individual intentions and public behaviour, especially group behaviour. It cannot be acceptable that parents dread taking their children with disabilities into the streets of their home

towns in Albania or, as later sections of the report show, live totally within the walls of their own homes, neither going out nor having visitors.

The public education, advocacy and media relations role of ADRF is an extremely important one that needs and deserves sustained financial support over a prolonged period of time. Much of their effort has gone into the publication of excellent written materials informing families, professionals and the public about many aspects of disability. This needs to continue, as does the work of other NGOs such as MEDPAK and Jeten Ndhmoni, which function in local areas rather than on a national scale. The development of Inclusive Education (see Section 16 of the Report) will also make a significant contribution. ADRF's training module on developing inclusion is a positive step and its further development and its implementation across all of Albania's kindergartens and Basic Schools should be a shared target between ADRF, other competent agencies and the Ministry of Education (Recommendation 3).

The twin approaches of empowering families to feel that they have an absolute right to respect and inclusion for their children in their communities and to educating the Albanian public about valuing diversity of abilities are both necessary. NGOs and more experienced and confident parents have a key part in the former by quite deliberately increasing the 'visibility' of children with disabilities in their own communities. NGOs and ADRF, supported by the Government and Donors, and the Albanian media of all kinds are the essential partners in the latter.

It may be that in a society in a state of transition to the 21st century, additional means to propagating information need to be further exploited, not only or mainly through written material but through posters, TV Spots, inclusion in informative non-sentimental ways in TV or radio plays and serials, etc. It is so very easy to follow a path that leads to children being viewed as objects of pity, or as beneficiaries of the charitable and (very public) benevolent acts of well-known personalities, or even as long-suffering little heroes. It is much more useful and inclusive that they be seen as children who live as normal lives as possible with parents who aspire to normality and who wish to be accepted normally and politely in their own community (Recommendation 4).

Section 3: Ethnic and linguistic minority issues

While legislation does exist to safeguard linguistic minorities rights it did seem to us that thinking about conscious and unconscious individual and institutionalised discrimination against ethnic and linguistic minority families with (or indeed without) disabled children is at a rather embryonic stage in Albania. Institutionalised racism is defined by the UK Commission for Racial Equality as, 'Organisational structures, policies, processes and structures which result in ethnic minorities being treated unfairly and less equally, *often without intention or knowledge*' (Richardson and Wood 2000: 34).

The lack of very obvious debate in Albania is almost certainly because of two key factors. The first is that, because of Albania's history of being 'shut off' from the rest of Europe for so long and having had few *recent* immigrants from countries other than Kosova, Albania has been less involved than other European countries in the unpleasant racism that has become so prevalent in many parts of Europe. The second reason is because of the broad and calm acceptance of the existence of many *longer-established* minorities in Albania; Greeks, Macedonians, Serbs, Montenegrins, Vlachs, Roma and the more integrated but ethnically Roma 'Egyptians', to name only some of the more numerous. Albanians themselves are perhaps more familiar with the unpleasant and humiliating racism and other forms of discrimination that they experience when travelling, trying to emigrate or when faced with the ignorance of some international 'helpers'. In a similar way, perhaps, internal migrants from less developed parts of Albania may feel undervalued and rejected by more sophisticated and longer established Tirana householders.

The lack of widespread awareness and of more obvious forms of racism does not, however, mean that it does not exist and that it may not develop as Albania becomes increasingly part of the mainstream of Europe and as the socio-economic gap between 'haves' and 'have nots' in Albanian society become even more apparent than they already are. NGO representatives working among Roma communities suggest that Roma adults and children do actually experience discrimination and societal disadvantage,

I would say there is prejudice against them, less is expected of them or they may be blamed for things for which they are not responsible. They should be in school but I am not sure that they are always welcomed there.

(Representative of NGO working within a Roma Community)

ADRF produce an excellent range of public, parent and NGO education and training leaflets but acknowledged during our interview that they had not produced these in minority languages or in alternative forms such as Braille or video clips. Such an undertaking would be expensive for ADRF within its own resources but could be an appropriate package for a Donor project (Recommendation 5).

One of the requirements for membership of the European Commission is national accountability in relation not only to general equal racial and linguistic opportunity but also to monitoring factors such as the interface between minorities and disability and between minorities and access to medical treatment and to educational placement. In many countries, including the UK and the Czech Republic, some aspects of inequity were identified and had to be rectified. Features of usually unintended institutionalised discrimination that may occur include *over-representation pro rata* of minorities in culturally non-valued contexts and *under-representation pro-rata* in culturally valued contexts. If this were so in Albania, then one might expect *more* minority children with diagnosed disabilities than *pro rata* either not in school at all or, debatably, misplaced in schools for children with learning disabilities. One might also expect fewer of them than *pro rata* receiving specialist medical care or in schools for children with sensory impairments.

In three out of the five special schools for children with mental disabilities that we visited it seemed that there may have been more Roma pupils than might be expected *pro rata* from the proportion of

Roma estimated to be within the Albanian population – 5%. (no attempt at estimating was made in the other two schools). This might be explained either by the location of schools near large Roma settlements or by negative discrimination from local mainstream schools. Only proper investigation could clarify the matter. In four of these schools Head Teachers remarked on the frequent absence from school of Roma, but not of the more assimilated 'Egyptian' children.

Another area of concern, especially in relation to the interface between minority children and possible learning disabilities, is the way in which children are assessed for possible placement in special school. This is generally by an internal school 'panel' of experienced staff but there is also external assessment of children by a developmental psychologist or a psychiatrist/neurologist who has some individual professional choice in how assessment is carried out. The child is usually seen out of his or her own home in strange surroundings by this specialist, who may also use - albeit only as a general indicator - some items from standardised tests such as the Stanford Binet tests for measuring general intelligence. Children generally perform best in their home environment and may be very inhibited in strange surroundings. Individual items extracted from standardised tests are neither valid nor reliable measures of ability, even when used on the population on which they were standardised. This referral to a specialist may therefore have doubtful value, despite the good intention of such guidance and of the professionals involved. Parental information about the child's capacities at home, a trial period in the school under the eyes of experienced teachers, perhaps with an observation visit from a psychologist, may produce a more realistic and holistic view of the child's potential than any pre-entry exercise. Some pre-entry assessments also involve oral questioning of children. A child whose first language is not Albanian or a child from an illiterate or uncommunicative background would perform poorly, regardless of innate ability. (The question of assessment of children with disabilities recurs in Sections 19 and 20). The risk of possible 'misplacement' of children is another good reason for education to move towards greater inclusion of all children in their local schools (see Section 16).

Our discussion with a senior official in the Ministry of Education made it plain that the Albanian Government was already aware of some concerns in relation to pupils from ethnic and minority communities. At that time it had been suggested that the issue might be addressed in the Ministry by the same section that is responsible for the education of children with disabilities. This would seem to be very appropriate and would allow the difficult interface in education between minority populations and disability to be confronted before it becomes contentious. Although our team discovered no evidence, there are also potential problems related to children with disabilities from ethnic and linguistic minorities and access to both medical treatment and to financial Social Benefits. The inter-relationship between disability, minority status and equity in access to services for children should be examined carefully (Recommendation 6).

Section 4: The Albanian Government and disabled children

The overall Governmental responsibility for children with disabilities is largely delegated through the various Ministries and their Governmental Organisations. Legislation can be perceived as a more centralised role, albeit usually drafted by Ministry-based officials. Nonetheless, it would generally be expected that some co-ordinating role could be expected of the Government. The impression gained by the Consultants was that co-ordination was neither visible nor evident in the working of GOs, nor - more understandably - in the links between GOs and NGOs, other than to a limited extent between GOs within the same Ministry and NGOs associated with them. Section 6 of our report draws attention to some significant problems that better central organisation might have prevented. Albania has had such a difficult past and recent history that such a criticism may seem to lack understanding of the problems in achieving 'joined up working'. We certainly *do* appreciate improvements that have been achieved even when they do not appear to fit into a nationally co-ordinated scheme. However, our view is that, if the needs of disabled children are to be met, 'joined up working' is a necessity, not an option. Without it, parents or parent-based NGOs themselves often have to struggle to make connections between the different services that their children require.

Albania is a signatory to the UN Convention on the Rights of the Child. We have already referred to Article 23 and the first part of Article 24 that have *specific* relevance to children with disabilities. However, it is also important to remember that the other Articles are applicable to *all* children and therefore the dimension of children with disabilities has to be considered in relation to each of the Articles. Albania's signature was ratified in February 1992 and Albania should, therefore, have reported on progress to the UN within two years, and thereafter every five years, through a state Committee convened for the purpose. However, Albania is only now in the process of consulting on its draft first report (Albanian Government 2002b). This draft report refers in Paragraph 318 to 'disabled and retarded children' being 'part of the wide community of disabled people in our country'. A more inclusive wording might have suggested that they were an integral part of Albanian society. The document has made a number of relevant references to children with disabilities but many of these do not indicate whether, for example, provision is new or was already existing at the time of first signing the Convention. It would also not be possible to deduce the position of children with disabilities because of lack of precision and quantification in the draft as it currently stands. Salient points were not always listed under Article headings nor were they consistently cross-referenced to them from other Article headings. We appreciate the difficulty in making official responses to such UN documents, but would suggest that for Albanian and international planning purposes a more structured response specifically in relation to children with disabilities would be useful. We understand that the Children's Rights Centre of Albania (CRCA) is co-ordinating NGOs' responses to the Government's draft report into a single coherent responsive 'shadow report'. We hope that our report might make a useful contribution to the Government's response or to the CRCA document.

In our discussions with ADRF we were told of their strong support for the development of a National Strategy on Disability. This would be guided and supported by a committee comprising GO, NGO and Associations associated with the rights of various disability groups. ADRF's view was that the Ministry of Labour and Social Affairs should have a lead role in such a development. We would like to suggest that there is a need for matters specifically relating to children with disabilities to be considered in a separate but related forum that brings together Education, Health and Social Services, GOs and NGOs, children's rights or advocacy groups and parents' associations. We acknowledge a wide range of common ground with the concerns of adults with disabilities but would not think it wise to have the Children's Committee simply functioning as a subsidiary group. We also have some reservations about the Ministry of Labour acting as a sole lead Ministry when, as we explained before, we believe that Education and Health need also to be very much engaged in the issues, both separately and in collaboration. In relation to children, the key Ministry for all children could be seen as the Ministry of Education, especially with the UN drive towards 'Education for All'.

One possible formula might be to have a single smaller overall executive committee on Disability, chaired by a senior non-Ministry Government official, which would receive reports from two larger working committees. These two committees would focus respectively on adults and on children but would meet for some joint sessions or in all-age sub-groups to consider issues of mutual and overlapping interest. We consider that both groups should bridge all the relevant Ministries, GOs, NGOs and Associations. If lead Ministries were considered essential for smooth working - and this may not necessarily be so - then Social Affairs might lead the adult-focussed committee and Education the children-focussed committee. The key tasks of the child-focussed committee would be to establish a national strategy for children with disabilities that attempted to ensure a smooth onward flow of development that eliminated overlaps and confusion (see Section 6), and that enabled gaps in essential provision to be filled as resources became available (Recommendation 7).

While recognising that Ministry responsibilities do have party political and economic implications, we would like to make a plea for greater stability in Ministry and GO key administrative posts. As those who hold such posts are themselves aware, progress inevitably falters when political change results in total responsibility change. Human services do require fresh ideas to be introduced but they also benefit enormously from the build up in knowledge and know-how that longer-term position holding brings about. Disability is essentially a matter that should be taken as far as possible out of politics or accorded some 'battle free zone' status between political parties so that progress, so long awaited, may be optimised (Recommendation 8).

Finally, we would like to emphasise that any measures taken by the Government to improve road, rail and public utilities infrastructures, and to spreading essential human services (medical, health and social services) across the country beyond Tirana will not only reduce internal migration in the longer term but will be an enormous relief to disabled children and their families who live beyond the central and better connected parts of Albania.

Section 5: The role of Non-Governmental Organisations

We undertook a strategic sampling procedure in our meetings with NGOs (see Appendix 1), holding discussions with five International NGOs and six Albanian NGOs. We had also previously circulated a questionnaire pro-forma (Appendix 4) to the NGOs that we subsequently visited and to ten others thought to be involved in the provision of services either specifically to children with disabilities or including them among other children. Only six forms were returned fully completed, reflecting both the pressure of work under which NGOs work and, to a lesser degree, some level of secrecy with which NGOs guard information about current or planned operations. We had not intended to provide a 'directory' of GOs and NGOs such as that published by Handicap International (2000), recognising that much data in the transitional state of Albania can only be accurate at the time it is gathered and may, even then, fail to indicate the critical issues in the area of disability.

The data gathered formally and informally gave us some indication of the range of activities in which NGOs were involved. It also confirmed our view that, while the various roles they are currently playing and have played in the past are extremely significant, the patchwork quilt of services that they create also has holes and weak areas within it and its composition is constantly changing. NGOs that have seemed substantial and important vanish because of financial or personnel problems or, in the case of some International NGOs, because other countries' new crises summon them. Meantime, other NGOs stagger on unable to achieve their aims as fully as they wished because of their inability to attract sufficient funding.

Some of the areas in which NGOs have been involved with children with disabilities and their families include; educational accommodation for children, support for inclusive education, development of therapy services, establishing day centres for children and families, publication of public and professional training information about disabilities, provision of actual professional training both short courses and full professional training (see also Section 20), provision of new residential accommodation and care, updating and refurbishment of residential and day GOs, assistance in claiming financial benefits, advocacy on behalf of babies with disabilities who are at risk of abandonment, care and adoption of children without families, improving access to public and service buildings, provision of wheelchairs and prostheses, identification of children and data-gathering, home visiting programmes, parent mutual support, child advocacy, etc. The list is extensive but very far from exhaustive. A desk study carried out on behalf of Save the Children in May 2002 found that there were about 480 benefiting children with disabilities within NGO locations. A further 600 children within family settings were also supported in various ways by NGOs. Many NGO activities and achievements are noted in relevant Sections of this report.

However, the list highlights that many extremely important and some absolutely vital services are provided by NGOs that might, in most other European countries, be provided by either GOs or by NGOs with longer-term core funding from Governments or with ready access to very substantial charitable funds such as national lotteries. NGOs, as we have already indicated, tend to be transient by nature, yet they are probably still second in line to families in the care of children with disabilities. It is not surprising, therefore, that families feel insecure and that many children and families are without any resources or services beyond the family itself.

In the past, and still now to a slightly lesser extent, the pattern of development of NGOs was to start as an international NGO, staffed by international personnel and Albanians, then to become a local NGO scaffolded by its international 'parent' NGO, then, ideally, to develop a partnership with a Ministry or with a substantial international or Albanian funder/Donor. A less desirable outcome might be a series of brief marriages of convenience with other small local NGOs. Plainly these are simplistic models.

Equally plainly, survival depends on the formation of partnerships with useful and, hopefully, rich partners. This requires extensive networking, project planning and proposal writing.

What we look for in partners is: longer-term funding and commitment, a shared view of the project, reliability and mutual respect.

(Albanian NGO Director)

Well, finally we succeeded, ten years of struggle, lots of partners here and internationally, they came and went but we stayed on, lots of begging, and now finally we are part of the Ministry. But I am exhausted and so are all the people of my generation.

(Director of a Centre, previously an Albanian NGO)

For small NGOs, however valuable the direct work that they do with children and families or with professionals who work with them, this competitive search for survival erodes the volume and sometimes the quality of the actual work that they can do.

I am so tired of writing proposals and looking for partners. We know our work is good and that it is necessary but the kind of community projects we run don't seem to be high enough on anyone else's priority list. I can't write any more proposals and work at the same time.

(Representative of small international NGO)

One of the major difficulties for a country in transition is its capacity to manage and co-ordinate the offerings of international agencies, to ensure that they are culturally sensitive and that they fit in to the 'broader plan' of the relevant Government development plan. The employment of extremely able Albanian nationals within international organisations is mutually enriching and also addresses to a large extent the issues of cultural sensitivity. However, we think that, as our previous Section indicates, there is a lack of a coherent overall strategy. If the proposed group to develop a National Disability Strategy for children with disabilities acted as a forum, not only for planning but also for critical scrutiny of NGO projects in the area, then the 'patchwork quilt' might have fewer holes and be of a more consistent quality. Some projects might be linked to GOs or offered some core Government funding, if and when available.

The increasing involvement of people with disabilities themselves and of parents of children with disabilities in formation of NGOs and of Associations is an immensely positive development. Coleridge (1993) and Hastie (1997), both involved in OXFAM's international work in traumatised countries, suggest that there may be particular opportunities for growth in disability rights movements in countries emerging from trauma as restructuring begins and external influences enter previously closed or disrupted environments. This is certainly evidenced in Albania although some have been subject to fracturing membership or difficulties in sustaining projects.

Analysis of our respondents' interviews gave some interesting insights into what are thought to be key factors in NGO success and particularly success sustained over several projects. We have illustrated the points with a series of quotations that relate to one multi-project Albanian organisation working in a rural area and in several medium sized towns. This organisation has carried out an identification search for children with disabilities and built up a comprehensive record system, developed an inclusive education programme in collaboration with the local Education Authority, has a flat for visiting parents, runs a Day Centre for occupation and therapy activities and offers support of various kinds to families including advice. The NGO's partners have included Children's Aid Direct, UNICEF and Save the Children. Many of the points made could have been made also about another organisation that we visited in Tirana.

Profile of a successful NGO

She's a parent and a teacher and he's a lawyer and they are parents themselves so they have credibility and know how to get things done. They just keep going quietly but persistently.

(Director of an International NGO of the couple who lead the organisation)

We wanted to work with them and the Ministry agreed. After that we asked our most communicative teachers to work with the project and it has worked really well for everyone involved.

(Local Director of Education)

Anne (a British volunteer from the largest UK NGO for people with mental disabilities) stayed with us for a year and just shared everything she knew with us. She comes back to see how we are doing and encourages us.

(NGO's organiser)

She's a mother too – she understands how it is, so we can talk about everything and she knows everyone so well round here. We trust her.

(Mother of daughter with severe mental and physical disabilities who uses the day centre)

Working here has given me a sense of purpose and renewal. It's good for the children, good for the community and good for me!

(Volunteer pensioner who helps in the Centre)

I help with the records. It's something I can do. Yes, I feel useful and now I would like to train in computers if there was a training place near here.

(Young woman volunteer at the Centre who is a wheelchair user and who was unable to complete her education after an accident)

The NGO above shows how a large and efficient organisation that now covers multiple substantial projects and has international and Governmental partnerships can flourish from small beginnings. However, in examining the reports from present and past NGOs and listening to parents, it seems that there are areas of Albania – particularly the far north-east and the inland and coastal far south but even in some medium sized towns – where there is a dearth of NGO and GO activity.

We really need more NGOs here. Why don't they come? Well, they do their business in Tirana, there are more people there. It is really a vicious circle. But they have to realise there are children with very real disabilities and needs over all of Albania.

(Director of GO in southern town)

While the population is sparser in the most distant areas, it is probable that there are children and families there whose needs may be even more acute than those in more populous areas (see Section 8, 'Invisible' children). This might be tackled in an imaginative and collaborative way by the larger NGOs and the Government, by the employment initially of a peripatetic research and development officer to work with Local Authorities in these areas to map possible projects (Recommendation 9).

There is a scarcity of Albanian industrial and business partners for NGOs. Two possible ways forward are to allow tax concessions to donor or NGO partner companies or to come to an ethical agreement on advertising. Business-NGO partnerships could be the focus of a sub-group – involving business managers - of the proposed children's National Disability Strategy committee or of the over-executive group for both child and adult strategy groups (Recommendation 10).

Many NGOs and especially parent organisations, seem intent on having their own premises yet these can become a financial and maintenance burden. Local authorities could keep a list of local NGOs to facilitate the sharing of premises, especially in locations that would offer opportunities for increasing levels of inclusion in the ordinary local community wherever possible (Recommendation 11).

The illustrated 'successful NGO' was fortunate in having the support of an international volunteer who acted both as a mentor/adviser and as a source of ideas. The level of experience within Albania itself is such that appropriate Albanian mentors do now exist. The Government or the relevant Ministry could be asked to subsidise expenses-only mentoring visits of approved experienced practitioners to new or struggling NGOs and Associations (Recommendation 12).

Section 6: Efficient cover of work to be done: Gaps, 'overlap' in activities and role, and dispersal of energies and activities

There is still much to be accomplished in work related to ensuring a good quality of life for children with disabilities and some of this will be expensive. This is not disputed. However, one of our intentions in carrying out this research was not only to highlight gaps in provision, but also to identify overlaps or confused responsibilities in work that result in wasteful dispersal of energies and activities. Further time, money and sometimes goodwill are wasted in later efforts to clarify such confusions. We have identified gaps in the individual Sections to contextualise them and have highlighted many of them in our Recommendations (Section 22) rather than simply listing them in one Section. We will focus in this Section on what we believe to be two very substantial areas of overlapping work and responsibility and two that are less substantial but still important.

The first substantial overlap is in the quantification of children with disabilities. In the next Section, 7, we discuss the advantages and possible problems in trying to identify Albania's children with disabilities. In the meantime it is important to note that a number of agencies are involved, or planning to be involved, in this area and that the sense of collaboration is currently missing. This is not a malevolent or deliberately competitive or exclusive situation, more one of simultaneous ideas and lack of 'joined-up' planning. Both the public information leaflets and the discussion of one of our team with the National Monitoring Centre for Disability (NMCD) (also known as the National Observatory of Handicap, initiated as a project of the Associazione Volontari DOKITA, funded by the Italian Department of Social Security in the Albanian Ministry of Labour and Social Affairs) made it plain that one of NMCD's roles was to gather data about children with disabilities. One of the leaflets specifies as just some of its extensive lists of activities the following:

- a) Initiating *distribution of information and management of a data bank*;
- b) Setting up a *local information system*;
- c) Searching for means of *co-ordination* between individual disciplines, institutions and professionals;
- d) Gathering *essential data* provided by the institutions, associations and organizations working locally;
- e) Becoming a key centre for the *exchange of information* collected from all interested public and private bodies.

It also invites collaboration but it is unclear how far its collaboration may extend and under what terms collaboration will be undertaken, for example, whether it envisages collaborative planning or only information sharing and whether its collaboration is free. It is also not clear whether other Ministries have 'equal rights' in the organisation, or if the Ministry of Social Affairs has a priority claim to its time and efforts. The discussion with our team member suggested that NMCD's data-gathering would not begin until the latter part of this year.

The Ministry of Education and UNICEF have announced a joint project to identify children with disabilities across Albania with a view to enabling planning for inclusive and special schools, a valid reason. ADRF had also suggested, in discussion with us, that one of the tasks of the working group that might be set up to develop a national disability strategy would also be to ascertain statistics on disabled people. They did not mention NMCD's involvement although, if the Ministry of Social Affairs were the lead Ministry, this would be a logical connection. Meantime, two local NGOs, MEDPAK in Librazhd, Elbasan and Peqin areas and Ndihamoni Jeten working in two districts of Tirana, have already undertaken extensive excellent work in identifying and gathering data on children with disabilities in their respective areas. Ndihamoni Jeten's work extended also to young adults and is longer established in one district of Tirana while just beginning work in another. We discuss issues about data gathering in the next section but at this point it is simply important to point out that '*the more the merrier*' is an adage that does not necessarily apply in data gathering! **We have made a strong recommendation (Recommendation 19) in the next Section about this issue.**

Another worrying area of increasingly confused overlapping interest and involvement is that of the education/training/development of children with mild to moderate cognitive disabilities. It was apparent during our visits to GOs that children who could be described as having such disabilities are currently placed in three different main systems, special schools, mainstream schools and day centres. Those attending mainstream schools may be found either in mainstream classes or in the small number of special classes that have been developed recently. Those attending special schools are generally in schools for children with mental and sometimes with additional mild physical disabilities (special needs) but there are also some in the School for Blind Children and to a lesser and not officially recognised extent in the School for Deaf Children. Some may also be found in residential development centres and there are almost certainly many among Albania's children who are not currently in any provision of any kind. Diagnosis of such difficulties is not always straightforward and issues such as socio-cultural deprivation, ethnic and linguistic minority status, sensory difficulties, and cerebral palsy can all confuse the picture. Often only time, observation and cognitive stimulation will tell the level at which a child may be able to function. In many cases, however, children's placements are decided more on the basis of availability of provision rather than on suitability of provision for the individual child. Most establishments are full to capacity or over-full.

While currently the Ministry of Labour's Residential and Day Development Centres tend to have a very mixed population of older children and even adults with mild/moderate to very severe and occasionally complex disabilities, a recent policy change (see Sections 14) has approved a change in the population so that they will now focus their attention on children with mild/moderate learning difficulties. (This policy change is discussed in more detail in Section 14). The overlap in populations between the various kinds of provision will therefore increase. This decision appears not to have been undertaken in consultation with the present Ministry of Education personnel. It could be argued that, while the *quantity* of provision is currently inadequate for *any* group of children, perhaps overlap of role in relation to one group of children does not matter. We would dispute this for a variety of reasons:

- ❖ The staffing levels, qualifications and general conditions are different in schools and centres and also varied among centres.
- ❖ Centres are managed at government level by the Ministry of Labour and Social Affairs and schools by the Ministry of Education. This is at a time when the Government has committed through the UN Convention on the Rights of the Child to develop Education for All, and has also just passed legislation on inclusive education. If the centres provide education, however defined, should they not be managed by the Ministry of Education?
- ❖ The changed focus of the Ministry of Labour and Social Affairs leaves children with severe learning difficulties without access to GO occupation/education/ training and appears to suggest that they are not capable or worthy of development - that they are 'disposable' in ways that children with lesser disabilities are not.
- ❖ It is confusing to parents seeking for an appropriate placement for their child to have two different systems.

This confusion and division of responsibility has been found in other European countries to be highly problematic to resolve, especially when it is allowed to become established practice.

We make a number of recommendations in relation to this and other issues in Sections 14 and 15. Meantime we recommend that relevant officials of the Ministry of Education and the Ministry of Labour and Social Affairs have regular meetings to ensure that policy developments in relation to the education/training/occupation of children with disabilities harmonise. One possible *longer-term* scenario they should consider is that:

- ❖ the Ministry of Education take over responsibility for the educational / developmental programmes of *all* children, ideally mainly in partnership with Local Authorities within

- mainstream schools, but with some special school and special class provision as necessary, and that
- ❖ the Ministry of Labour and Social Affairs assume responsibility for residential accommodation for all children with disabilities who require this (but *not* in schools with attached residences such as the Schools for Blind and for Deaf children which would remain the responsibility of the Ministry of Education), and for all adult specialist day and residential provision. (Recommendation 13)

Such a scenario plainly has substantial implications for funding, staff recruitment, training qualifications (including up-grading qualifications of existing staff in centres and in some schools), and conditions of service. It would also bring into education many children with disabilities who are either currently not in education at all or are currently in Ministry of Labour and Social Services residential and day provision – this is discussed in more detail in Section 15. Where other countries have adopted such approaches, social service day centres have been ‘converted’ gradually into schools and residential centres have sent children out into the local community mainstream and special schools to receive their education. Underpinning such a transition is the conceptualisation of education as a holistic developmental process. This process includes academic learning but also subsumes life skills and moves away from totally fixed curricula to curricula that may be differentiated to some extent so that programmes fit children rather than the other way round. The *Normative Dispositions for Pre-University Education, Article 57, the Education of Children with Special Needs* (Albanian Government 2002a) greatly facilitates such developments.

One of the serious outcomes, however, of the current change in policy within the Ministry of Labour and Social Services is that young or older adults with more severe mental disabilities currently resident in the Residential Development or placed in Day Centres may be displaced.

The decision is already made. We want to work with young people with milder difficulties because it is possible to achieve something with them.
(Director of Day Centre)

We suggest that the Ministry of Labour and Social Affairs should plan optimally normalised living in family size and type home for these adults and any others who require residential accommodation. NGOs and Donors should also be involved in this development. **No further medium or large residential institutions should be opened** and, wherever possible, adults who have lived together over some years should be grouped together in any re-housing exercise. We disagree strongly with the view that children or adults with severe mental disabilities cannot learn or develop further and that they are not worthy of optimal living conditions (Recommendation 14).

Finally, in relation to the Ministry of Health, there are two Centres, the National Centre for the Development and Well-being of Children, Kombinat, (previously the Dystrophic Hospital) and the Department of Mental Health of the Institute of Public Health (previously the Child Development Centre). Both have been helped by a diversity of funders and partners as well as by immense internal efforts to achieve standards in practice and in physical environment that are comparable to good practice in other European countries. It seems that their roles are significantly different in most respects but both appear to be involved in working in child protection and positive family interventions, and in Autism.

Both also employ educators and in the Department for Mental Health a teacher is paid for from parental contributions. While it is certainly appropriate to have educators or teachers available if children are resident in clinics or hospitals, it might be suggested that the Ministry of Education should be the provider of that education. (The National Centre has residential facilities for distant families but is otherwise a daily resource and the Department of Mental Health is a daily resource.)

Both Centres are expected by the Ministry of Health to undertake a great diversity of other tasks including professional education/training, production of information and project development and support. In addition, the Department of Mental Health has been asked to undertake research and the National Centre is expected to undertake much-needed outreach work in areas outside Tirana to develop the professional capacities of other medical centres. These are demanding expectations and while the National Centre appears to be well resourced to meet them, the Department of Mental Health with only six staff currently is not. We recommend that the Ministry of Health clarifies any overlaps and, where the Centres continue to function with some overlap, facilitates collaboration between the two Centres to ensure smooth working relationships (Recommendation 15). We have made some suggestions in relation to children with autism in Section 17).

Section 7: Numbers of children with disabilities and data collection

In the previous Section of the report we pointed out that there was already a number of agencies and at least two Ministries involved in planning a 'census' of children and/or adults with disabilities. Many countries have attempted this and most have had substantial difficulties in deciding what data they wanted or needed and how it should be gathered. Several countries have lost substantial time and money because the planning stage of their exercise was not sufficiently detailed or because they assumed wrongly that a diversity of existing 'registers' could be brought together in a satisfactory way. Most countries use their intermittent national census to establish some very basic data and this is immensely useful. We would suggest that those Government bodies that plan the Albanian Census should include questions on disabled family members and that they should draw on the experience of other countries to do so (Recommendation 16).

It is possible to estimate the numbers approximately although we cannot identify children in an individual way without a census of some kind. Within European countries with reliable statistical data a rough rule of thumb is that there will be around 2% of the child population with moderate, severe, pronounced and specific disabilities, and a further 8-10% with lesser difficulties. Over and above such children will be others with mild and transient difficulties in learning. Albania has around 1.2 million children age 0 -18 in 2002. Within that age group one could therefore expect to have **120,000 children with some degree of disability or learning difficulty** of whom around **24,000 would be at the more severe end of the spectrum** with half of them - **12,000 children - having very severe disabilities**. Albania's higher perinatal and early infancy death rates (40 deaths per 1,000 live births estimated in 2001) would reduce that last figure as some of the perinatal and early infancy deaths are likely to be children with the most severe disabilities. However, this probable reduction would be offset by a probable higher incidence of disabling perinatal and infancy trauma. 12,000 –24,000 children with moderate/severe/profound disabilities would therefore be reasonable figures on which to base some plans for provision.

Of these children, approximately 235 are in Residential Developmental Centres, 113 in Day Centres and 794 in Special Schools and Classes, giving a total of 1142 in GOs (see Appendix 4) and an estimated further 1000+ children are probably in contact with some kind of NGO (Save the Children 2002) (see Section 5). The figure of 1142 in GOs is an overestimate of 0-18 year olds since many of the Ministry of Labour and Social Service GOs have a number of clients who are over age 18 (indeed the Day Centre in Saranda now has *only* adults and so was discounted among GOs for children). There are also children with disabilities in orphanages – Red Barnet (2002) estimates about 79 children or 17% of all children in State orphanages. It is known that there is also a small number of currently not totalled children with disabilities in private/NGO orphanages. Other children with disabilities are already in mainstream schools. However, few if any of the children in mainstream schools have severe disabilities. There are also children with disabilities of school age who have attended mainstream or special school for a period of time but have 'dropped out' of the systems. We cannot be sure what degree of disability the children counted as being in contact with NGOs have, nor the children with disabilities in orphanages (see discussion and recommendations on this issue in Section 14). ***We can, however, be reasonably sure that there are at least 9000+ children with very significant disabilities and, more debatably, up to a further 11,000+ children with lesser but still significant disabilities not receiving GO or NGO services.***

In Section 8 we explore the issue of 'invisible' children among those estimated 20,000 children and reasons for their invisibility within society.

While knowledge of numbers is essential, numbers alone are an insufficient basis for planning. We discuss later in this Section the possible specification and parameters of data to be gathered. Does acquiring data necessitate a new search or does it exist already? Local offices of the Institute of Social

Insurance are responsible for payments of individual disability allowance. This Institute should be a potential source of statistical and personal disability data. However, some families may not apply for a variety of reasons explored more fully in Section 12 of our report and some may not even be aware of the Benefits system at all.

Maternity hospitals, paediatric health units and hospitals and local medical practitioners are other potential sources of data, but with a high level of home births and many people living at a distance from medical support, these records will also be incomplete and very varied in content.

Local schools record all their enrolled pupils but we understand that schools are not required to record details of any child not accepted by the school, nor the reasons for not accepting or subsequently requesting that a child be removed unless he/she is being referred to a special school. We recommend that *every* child age five should be registered at his/her local school and that any child identified with disabilities/special needs at that time should have their details recorded and sent to both the local education authority Director for Special Needs (see Section 15, Recommendation 46) for onward transmission to the Ministry of Education, and to the local office of the Institute for Social Insurance, for onward transmission to the Ministry of Labour and Social Affairs. (Recommendation 17). We also recommend that any child who is refused admission to any Residential Developmental or Day Centre by the central admissions office of the Ministry of Labour and Social Affairs, or who is refused entry to a Special School, should have his/her details copied, with reasons for the refusal, to Local Authority Social Services and Education offices. Local offices should then follow up such cases and try to ensure some local placement (Recommendation 18).

The reality is that many families may still not register their child with a doctor, at a school, or to claim financial benefits. Both the NGOs that have carried out an identification have noted that, despite their local credibility and widespread networks, they were still 'finding' children with disabilities two or three years into their two programmes, one in Tirana, one in a mixed urban and rural setting.

Finding all children with disabilities is a major challenge but it is not the only one in this aspect of the work to be done in Albania. The nature and extent of the data to be requested is also important and the parameters of what is included in 'disability' or 'special needs'. What information about the children and their families will it be necessary/useful to include? Data requirement is, minimally, location, age, nature and degree of disability and health status of the child, and level of family support available in terms of income and caring competence. Updating, storage and security of paper systems is highly problematic. A computerised system must be considered as a priority but computerised systems are effective only if key suppliers of data and data processing staff have relevant and compatible equipment, software and skills to use them.

Informed consent of parents and of children, where possible, should be obtained for any system of data gathering. Gathering information of a detailed personal kind raises expectations of services, many of which Albania may not be able to provide in the short or medium term. Such ethical issues have to be part of the preparatory discussions. Drawing on the experience of other countries and benefiting from their mistakes and successes would be vital in the success of the exercise.

Collaboration of all interested agencies is necessary to ensure a full and efficient 'census' of children with disabilities. We recommend strongly that a working group comprising representatives of the Ministry of Education, Ministry of Labour and Social Affairs, the National Monitoring Centre for Disability, the Ministry of Health, UNICEF, the NGOs 'MEDPAK' and 'Ndhimoni Jeten' and at least one computer database expert be convened to plan this exercise and to detail its specification (Recommendation 19). This might also be an opportunity for the relevant Ministries to review their own institutions' record keeping.

Section 8: 'Invisible' children

This section has issues in common with Section 2 about Albanian society, and with the preceding and following Sections, 7 and 9, on identifying and counting children and on families. The ADRF survey (1998) of Albanian public opinion on disability illuminates many aspects of social attitudes and on 'visibility' of disabled people, including children. 'Visibility' is used in its sociological sense, meaning how far society 'sees' or 'recognises' a certain group of people and their needs and pays respectful attention to them. However, it is also used in its literal sense - some children with disabilities are simply at home all of the time and do not go out into their local community.

The ADRF survey asked interviewees (Page 8) about personal acquaintance within the family of someone with a disability. The data obtained was tabulated as a range of disabilities (Page 10) which the researchers suggest indicates the national profile of disabilities. They also suggest that it is similar to other countries. In their conclusions (Page 37: 1b) they assert that they have 'reliable responses to the degree of incidence of disability in the present Albanian society and types of disability'. These claims cannot be justified. The table shows a predominance of physical and sensory disabilities over mental illness and mental disabilities, whereas the norm of countries world-wide, and almost certainly in Albania, is just the opposite. Even allowing for inclusion of later onset sensory and physical disabilities associated with old age, it seems that mental illness in adults and mental disabilities in adults and children were under-reported because of being, again world-wide, a source of shame or embarrassment. P18 of the ADRF survey offers the key to this, suggesting that Albanian families prefer the label 'sick' for people with such disabilities, affording them care within the family but also, for fear of 'discrimination or ridicule' hiding or excluding them from a normal social life.

People with mental disabilities, particularly people with severe and complex disabilities and those who may look 'different', are sociologically more 'invisible' in Albania than other groups of disabled adults and children. Their parents are conditioned into acceptance of this invisibility and may actively seek it for themselves.

I have never met the mother, she stays in the other room all the time with her most disabled son.
(Local school teacher, neighbour of family with five disabled children)

He is not ready to allow his wife to bring the boy to our Centre. I think that to do so would be a public admission that he had a handicapped son who was not going to get better. And that is too painful and shaming for him.
(NGO Organiser about a young father of a blind child with epilepsy and profound learning difficulties)

Since he was born, people turn away from him. They prefer not to see him which is really sad because he likes people and wants to chat in his own way with them.
(Father of boy with mental and physical disabilities)

Our preface to the report, the father's story of his deaf child, is a reminder that parts of Albanian society are still very much affected by superstition, early religious or pre-religious beliefs and the concept of 'fate' or 'destiny' that encourages self-contained acceptance rather than an assertion of rights, far less of pride in one's child with a disability. Nor are such beliefs and emotions confined to less educated rural people. Some of the mothers that we quoted in Section 2 who found it hard to take their child out into their local streets were educated and very competent people. One such young professional woman, interviewed about her son who had severe autism and whom she clearly loved still said, 'I am sorry for my older son, that he has this shame in his family'.

There are other groups of invisible children with disabilities, less associated with shame and perhaps more forgotten and ignored. Few children with significant physical disabilities are in school or on the streets. Access is poor and although ADRF's subsidiary 'Miresia' makes wheelchairs for children they are still of a standard production. Many children with physical disabilities are not 'standard' shapes, nor do they sit comfortably in standard positions. The outcome is that they do not leave home and are actually, as well as sociologically, 'invisible'. This is also true of children with longer-term serious medical conditions.

Poor kids, they are sometimes here for several months for treatment and of course they lose their hair and then they get other medication so they put on weight. Then we say, 'Don't go near other children for a year to avoid infections'.

(Oncology specialist about her young patients with leukaemia and lymphomas)

For children facing a lonely and sometimes frightening future as many with serious medical conditions do, much could be done to link them to their peers in local schools and indeed to each other. We suggest in Section 16 that inclusive schools will try to offer some home education. Some NGOs are already facilitating this in inclusion projects. NGOs or donors might, for example, support projects to link young cancer patients or young people with cystic fibrosis to each other through a mutual support mobile phone network. While this examples focuses on only one sub-group of the 'invisible' children and young people, it highlights the need for both creativity and for the exploitation of modern technology as it becomes available in Albania.

There were indications too that some deaf children are 'lost' if they either do not apply to the school for deaf children, or if they apply and then are refused on the grounds of having unacceptable mental disabilities or only lesser hearing impairments. One such child was subsequently enrolled in a special school for children with learning disabilities which had no knowledge of how to work with deaf pupils. She stopped attending.

She is probably at home. We have no contact with the family now.

(Director of Special School)

We heard nothing specifically about children with severe specific language impairments throughout our visits but we know there must be aphasic children and children with cerebral palsy in Albania who do not have the alternative or augmentative means of communication that they might have in other countries. Autism is only now receiving wider recognition. We have made a recommendation in relation to both groups in Section 17.

Blind children with additional more severe mental disabilities are not in schools. Even blind children of normal or high ability in the special school for blind children may have a very low societal profile because of protective attitudes but also because of the lack of a qualified professional mobility teacher in the school.

There appeared to be no co-ordinated attempt to identify and treat young substance abusers (children and young people who ingest or inject drugs, consume alcohol to excess or sniff glue and solvents) although NGO personnel spoke of their known presence. While child addicts are beyond the scope of this study (see Recommendation 1), they are among the most socially, emotionally and physically vulnerable children in Albania.

However, it is important to emphasise that, where greater visibility *is* actually achieved through societal and inclusive educational measures, the gain is felt throughout the community and not only by its disabled children and their families.

You know, I think we have the feeling that we are doing the right thing for everybody – it has made us all better people.

(Head teacher of local basic education school involved in an inclusion project)

We would like, therefore, to make two recommendations in relation to children and young people who are currently 'invisible'. We recommend that NGOs and donors think of original ways, exploiting modern technology and developing de-centralised and outreach services, to enable children who need to be in their homes, hospitals or in other 'enclosed' provision (for example, children with very serious illness or deteriorating conditions) and their families feel better supported and better linked to the mainstream of life (Recommendation 20).

We also believe that there are many 'invisible' children who do **not** need to be 'enclosed' but who require more service provision suited to them, better transport arrangements and a warmer welcome in their local community. We therefore recommend that as further service provision for children and young people and other developments are planned in Albania that every effort be made to prioritise currently 'invisible children' with disabilities and other special needs and to ensure by legislative and educational means that the community is one that welcomes their emergence (Recommendation 21).

Section 9: Families of children with disabilities

We have already recommended in Section 2, Recommendation 2, that the Albanian Government should seek to strengthen support for family care of children with disabilities. A number of recommendations that should also contribute to improved family well-being also appear in other Sections.

No parent spoke negatively about their child, almost all expressing love and some pleasure at their achievements although some had found it hard to adjust their hopes and expectations to the very small signs of progress and the extremely slow pace of development in children who had the most severe disabilities. Having made that adjustment themselves, they were impatient and critical of professionals or members of the public who did not seem to value their child (see also Section 2). Nonetheless, many parents spoke of the support they received from their own parents and relatives and their other children. Some also had good neighbours.

If the weather is bad my neighbour will offer to do my shopping for me so that I don't need to get my son dressed up and push him in his chair to the market. And she comes to the house and we talk and laugh as friends and she likes my son.

(Mother of boy with physical and mental disabilities)

Many also spoke of their child's capacity to return love and to generate love in others.

Among the most overwhelming emotions expressed by parents was fatigue, both physical and emotional.

You expect to change nappies and feed a baby or a toddler but I am still doing it for a sixteen year old and I am tired. She has never slept well, so we take it in turns to get up. Every night of the year, every year since she was born, we are up three or four times a night.

(Mother of sixteen year old girl with severe mental and physical disabilities)

He has fits at night as well as during the day so we can never relax. We always worry about him.

(Father of six year old boy with severe learning difficulties and epilepsy)

ADRF had run a pilot respite care programme that offered alternative care for short periods of time for parents. They thought it failed perhaps because 'parents could not let go'. One mother whom we spoke with described her strong protective feelings towards her autistic son. She had been advised that he might be accepted in her local kindergarten but she was still hesitating, 'He is my weakness – it is a difficult decision'. We think that such protective feelings are entirely normal especially where parents, usually mothers, have been the sole carers for their children and especially where the children do indeed have complex problems that are difficult to deal with. Establishing trust in alternative carers takes time and demonstration of capability, warmth and trustworthiness on the part of the alternative carers. We suggest (Recommendation 22) that programmes that seek to offer parents respite or to start the process of inclusion should ensure that:

- ❖ the transfer of care is very gradual and within the control of the parent,
- ❖ parents may stay with the child in the respite or kindergarten/school situation until the child is fully settled,
- ❖ respite could be offered in the family's own home,
- ❖ whenever possible there should be continuity of personnel involved,

- ❖ a named person of the care establishment/service, of the parents' choice, should be freely contactable by the parent.

Several NGOs had run summer camping holidays at the seaside for families with their children with disabilities and their other children. This was undoubtedly a highlight in the lives of the parents and children who had this experience. Most of these families would not have been able to afford such a holiday and for many, with children with severe and complex disabilities, the practicalities would have been too much without the additional help that NGO personnel and student volunteers provided. We recommend that such opportunities be found for all families with children with more severe disabilities from time to time (Recommendation 23)

It was the best holiday of our lives, actually the only holiday since our daughter was born fifteen years ago, and our boys had a great time too. I felt years younger!

(Mother of girl with profound and complex disabilities)

Protection of girls is another issue of concern to parents, particularly girls whose appearance is attractive and who may have only mild or moderate difficulties. This also applies to sensorily impaired young girls, particularly deaf pupils. Parents and teachers feel that their social perception is not acute and that they are socially and sexually vulnerable.

We do not allow the girls out on their own. We cannot take the risk.

(Teacher in the school for deaf children)

We took her away from school when she was fifteen. She was showing an interest in boys and they in her and we were worried. She would not be able to explain to us if anything was wrong and we found it hard to explain to her.

(Mother of girl with mild/moderate mental disabilities)

Several parents spoke of their children's incontinence. This was very difficult to cope with, especially in families where there were less good sanitary arrangements and, in some simpler village housing, no possibility of a washing machine. Disposable nappies were very expensive and not subsidised, costing at least 2,000 Leka per month - nearly one third of the monthly disability benefit for their child. Non-disposable nappies were more likely to cause sores. In a country with large tracts of isolated and poor rural communities and in the inadequate housing of migrants who have moved to cities and the central areas, this must affect many people. We recommend that disposable nappies be provided at a reduced cost to parents of children with severe disabilities who are incontinent beyond the age of six (Recommendation 24).

Some children and young adults were non-ambulant - an extremely difficult situation for any family without its own transport and in villages without surfaced roads, and one that becomes more difficult with growth and increase in weight. It makes movement both within the house and beyond it very difficult although the provision of wheelchairs through 'Miresia' make a substantial difference. Nonetheless, in some families both the disabled person and their main carer - usually the mother - effectively became house-bound. There were fears too about risks in lifting. We recommend in Section 13 that social workers should have some responsibility for identifying children and families in need of mobility aids and other equipment such as lifting hoists.

My husband had hurt his back at work and while he could not lift my daughter I worried what would happen if I too hurt my back or became ill. Who would have helped us? My sister is in Italy and my brother is still far away in the village.

(Mother of girl aged 13 who cannot walk or sit up on her own)

Although mothers far outnumbered fathers at our meetings and mothers were still clearly perceived as the main carers in Albania, it was evident that many fathers were deeply engaged in both helping care for their children with disabilities and in parents' associations. Several NGOs had men volunteers and some training agencies specifically highlighted the role of fathers as being of great significance in the health of the family as a unit and in the mental and physical health of the mother.

Parents spoke of the difficulty in getting specialist medical attention when their child was first perceived as having a disability of some kind, of getting a clear diagnosis of any kind, in getting constructive advice, and of receiving on-going specialist medical surveillance. They also spoke of how centralised so many services were in Tirana, and of how expensive and difficult it was for them to get there. Dentistry was also a major problem for very many families. A range of recommendations about medical and dental services appear in Section 19.

I heard that they might have some clinics for handicapped children here in the north but we have not been contacted. He has not been seen by a specialist for ten years - really since they told us he was handicapped.
(Father of disabled son)

Many parents thought that there was still a lack of information about disability and especially, they thought, about the disabilities experienced by their particular children. Only two mothers with whom we spoke had found any of ADRF's leaflets for themselves although those who belonged to parents' or disability associations were better informed. As we have already suggested in Section 2, there is a need to look at diverse ways of generating information to parents, professionals and the public.

Families reported that there were some critical times for parents. We look at these in the following Sections; the time of diagnosis or realisation of disability in their child and the years immediately following that (Section 13), the time of school entry or, more commonly, of not being accepted for school (Sections 15, 16 and 17), the prospect of the likely void after the school, centre or child-related NGO services no longer apply (Section 11), and, the worst of all, what would happen when parents died or were no longer able to care for their child (Section 11).

However, it would seem appropriate to end this section with a spontaneous tribute to parents from a partially sighted pupil at the school for blind children. She also has two siblings with the same visual impairment. We had asked her what she would advise a friend who had a child who was visually impaired. She immediately realised that this was an indirect way of asking her about what *she* would do.

I would not change anything that my parents did for me. They moved to Tirana for our sake so we could be together and they supported us from the beginning.
Visually impaired girl (14)

Section 10: Siblings

Many of the parents we spoke with expressed concerns about their other children and the effect that having a sibling with a disability might have on them.

We were so used to worrying about our disabled daughter that when something was wrong with one of the others, at the time it seemed less important. But now we worry about it and feel guilty, perhaps not of neglect but of some loss in feeling. And we worry whether they were deprived of things they should have had because we wanted to do our best for our handicapped daughter.

(Father of three daughters, one of whom has Down's Syndrome)

Our older daughter is at University in Tirana now and I am glad that she has a chance to find herself there as I am sure sometimes that it was very difficult for her here.

(Mother of two daughters, one of whom has severe learning disabilities)

I used to keep my other two (children) in to keep their brother company as he could not go on the street. But they rebelled and I have to let them go out. Now our disabled son is lonely, he has the television and he has us but he likes young company and he should have it.

(Mother of a boy with physical and mental disabilities)

It seems that sometimes a sibling develops a special relationship with their disabled brother or sister, without being urged to do so.

I have parents, four sisters and a brother. Only my twelve year old sister understands me. She asked me to teach her sign language so we can communicate. I like being with her.

(Deaf girl (15) through an interpreter)

He responds to his younger sister. She has always been affectionate with him and helps him and you can see that he pays attention to her.

(Father of boy (17) with physical and mental disabilities and some autistic characteristics)

Sadly, in Albanian society it seems that siblings of children with disabilities may sometimes be stigmatised in the minds of others and that, for instance, prospective marriage partners may hesitate to develop a relationship with someone who has a disabled brother or sister. Some of this may be caused by fear of having extra responsibility, or of future children inheriting the condition, or it may be irrational prejudice. While public education will undoubtedly help this situation, we suggest that families should, where possible, be given clear information on genetic probabilities of familial incidence, if any, in siblings and in subsequent generations (Recommendation 25). Other children can also be cruel.

I had to go to my daughter's school to see her teacher and I took my son with me because there was no-one else to look after him. My daughter saw us there and she was ashamed and embarrassed. The other children saw him also and on the next day they teased her cruelly. I was so angry with all of them, including her!

(Mother of boy with physical and mental disabilities)

Much research has actually been carried out in other countries into the effects that illness and disability have on healthy siblings, some of it of dubious validity and reliability. That children are affected by their sibling's conditions is undeniable but, as Eiser (1993) points out, much research has been conducted from a pathological perspective, seeking evidence of childhood and later adult psychological and behavioural maladjustment. Substantially less work has been done from a pro-social perspective. Meyer and Vadasey (1997), however, reviewing a very wide range of good quality research about siblings of

children with disabilities, report a mixed but overall much more positive picture. Siblings do often lack information that is important to them, for example, about the possibility of them having a child with disability or of their disabled sibling dying. They do sometimes feel isolated, guilty and resentful about their sibling but only temporarily. They experience pressures from themselves, as well as from their parents, to achieve academically and sometimes to care for their siblings, and many worry about their siblings' and their own future. However Meyer and Vadasey also found that many research studies showed that siblings also have opportunities to develop very valuable human qualities - appreciation of family and loyalty to them, pride in their siblings' struggles to cope, sensitivity, human insight and maturity beyond their years - and that they become positively special people in their own right. It seems very probable that such findings would also be substantiated in Albanian families.

Section 11: After childhood – adult care and occupation

Perhaps we should not be writing about what happens beyond childhood in a report on the situation of *children* with disabilities. However it was clearly evident to us that parents of children with disabilities cannot actually enjoy their children's childhood if they are worried about their future. It was overwhelmingly the greatest concern of *all* parents with whom we spoke and some of the most powerful evidence of this is quoted below. The concern had two strands, the greater of which was simply, *'Who will care for them when we have gone or are not able to look after them any more?'*

In the past, and still within some families, there is a broad assumption that family members would assume the responsibility. With the increasingly small Albanian family size, with increasing internal migration and emigration and with continuing poverty, this can no longer be considered so sure, hence Recommendation 2 urging the Government to support family care of disabled members.

It is sad to think about your old age and death when you are just thirty, but I must.
(Mother of boy (6) with severe physical and mental disabilities)

I worried from the moment I realised how disabled she was, when she was just a tiny baby. While I was trying to feed her I would think about the possibility of me dying and that no-one else could look after her, that she might also die or have to go to a dreadful institution. I still wake up in the night with that fear and it is always with me.
(Mother of young woman (22) with Down's Syndrome)

It is really hard, we cannot take them with us to the grave but neither can we leave them above ground as things are now, yet it seems there is no middle way.
(Father of a girl with severe mental disabilities)

Other parents' thoughts had turned to the possibility of their other children taking on the responsibility but that did not seem to be a solution in which they had confidence.

We really have to know about the future. We all (parents) lie awake and worry about what will happen when we are gone. Who will look after them? Will it be our other children and then will their lives be darkened too? Albanian society is not fully prepared for this yet, especially thinking to the future.
(Mother of girl (18) with severe learning difficulties)

I have two younger sons and already they are saying, 'We won't look after her'
(Mother of a 18 year old daughter with moderate mental disabilities)

I try to encourage them (other siblings) to be close to her so that when we have gone . . . maybe they might . . . maybe
(Mother of 14 year old girl with mental disabilities)

I have two older sons as well as my (disabled) daughter. I wanted them to grow up without pressuring them with responsibility for their sister. I don't say that they don't love her – because they do love her. But, to look after her all the time ?
(Mother of young woman with physical and mental disabilities)

It is only by the implementation of Recommendations 2 and 14 (Supporting care in the family and providing family type care for older people with disabilities) that parents may feel less apprehensive.

The second strand of parents', and indeed professionals', concerns was about occupation for young adults. A number of NGOs do have workshops but it seems to be problematic to keep them going because of the intermittent funding situation of NGOs. Some workshops have tried to produce sellable goods without marked success although one NGO had a knitting workshop producing well-designed clothes. Another workshop in a Day Centre had some interesting art and craft work that it exhibited but did not attempt to sell. The same Centre had planned a pottery that could not function for lack of funding and wiring for its professional quality electric kiln.

Reasons given by our respondents for the need for occupation included making use of the skills and abilities that young people had acquired earlier in school and at home. Parents also highlighted that, by the time their children were young adults, they themselves would be getting older and would need some respite, at least during the day. The young people also needed company, not just to be at home with tired parents in front of television.

There are very serious concerns that the law on vocational training, employment and employment quotas for people with disabilities (Law Number 7995, September 1995) is not observed. Many countries have now abandoned quota systems and use positive inducements such as long-term Government grants to employers. Although the law also applies to children and young people there is no clear reference in the Government's draft response to the UN Convention on the Rights of the Child to its failure in this respect. With the slow increase in tourism there may be possible vocational opportunities in, for example, catering and service industries or in workshops producing aesthetically pleasing souvenirs. We recommend strongly that an NGO commission a consultant's report on prospects both for supported open employment and for part-special workshops (with a proportion of mentor non-disabled workers) and that some pilot programmes are established in collaboration with Employment Offices (Recommendation 26). We also recommend that vocationally orientated secondary education be developed for young people with mild to moderate disabilities. This should be in inclusive or semi-inclusive settings whenever possible (Recommendation 27).

Section 12: Financial support for families

We spent some time in trying to understand the Individual Disability Allowance system and the implications of the legislation (Law 7710, May 1993) as well as the list of mainly medical criteria for registration as disabled. We are not surprised that the 'system' is widely criticised by parents and by professionals, including those who administer it or adjudicate within it. We do also, however, accept that it is very difficult to produce a system that supports those who need it most and that provides some safeguards against fraud. We also appreciate the underlying humanity that Albania makes such payments while struggling within tight financial constraints.

However, at a time of widespread poverty and high unemployment in Albania, it still must be said that the Individual Disability Allowance is, in many cases, totally inadequate to cover the additional expenses incurred by having a child with a severe disability. There may be requirements for a special diet, additional heating, additional use of own or hired transport, extra bedding and clothing, specialist equipment and, one of the most expensive items and beyond the reach of some, purchase of medicine and some forms of medical treatment including surgery. It is entirely right that the allowance is not family income related and that payment is for every individual so that, for instance, in families with two or more children with disabilities, each child will benefit. Payment in such a case is now currently 6,800 Leka per month and a further payment is possible under more specific and demanding criteria. Welfare benefits are payable to any family with no member in employment and Individual Disability Allowances are not counted as income in claims for Welfare Benefits.

In order to claim the Disability Allowance, however, there is an extensive bureaucratic form filling exercise and the presentation of the child at the Medical Commission for Determining the Ability to Work (KMCAP) involving a medical examination, all on an annual basis. All the professionals with whom we consulted, including paediatricians working as KMCAP referees, social workers and NGO personnel working with children with disabilities and their families, agreed that many families found the process daunting and humiliating, and that there were undoubtedly families who were eligible and sometimes desperately needy but who did not claim the benefit.

There he is with a wife with physical and mental disabilities and five children, at least three of whom would be eligible for the Disability Allowance as well. It would make a huge difference in their life but it would mean coming in to town and I just don't think he is going to do it. It is partly that he is, maybe not frightened, he just doesn't want to take them all to the doctor and he is probably illiterate. I've told him we would drive them there and that I would fill in all the forms as I do for other people but he won't come. He is managing with the help of the extended family around him and he doesn't ask much from life.

(NGO manager about a father with four possible claimants in his family)

Key criticisms of the system are as follows:

- a. The process is difficult for families to understand and its bureaucratic elements may actually be so confusing that some families may not proceed with their valid claims. (While local social workers (see Section 13) and NGO personnel are increasingly supportive of claimants and ADRF have produced some guidance to simplify the official language of forms, this is not always sufficient to persuade some families. Both pride and shame contribute to their resistance but confusion is the main factor)
- b. There are few paediatricians with knowledge of disabilities working outside Tirana and, for this reason, significant numbers of families with children with disabilities for which there is not a clear diagnosis or whose level of disability is in doubt, are referred to the national KMCAP in Tirana. For many families with a child with a profound disability or in a very fragile state of health, or who have never travelled far beyond their village, such a journey is unthinkable.

- c. Illiterate families, those parents who themselves function at a very low mental level and very isolated families may quite simply never have heard of the Disability Allowance.
- d. The medical criteria given for disabilities are rather over-precise, so that children may meet them possibly 75-80% but not 100% and this can leave the decision in doubt.
- e. The criteria may also require a definite diagnosis in some cases and some conditions may either not have been diagnosed or be difficult to confirm absolutely.
- f. Despite external and internal criticism, the system and its criteria have not been revised since 1993.
- g. Regardless of whether a child has a lifelong severe disability, or even a terminal and rapidly declining condition, the child must still be submitted to the tribunal process annually if he/she is to be eligible for claiming the allowance.

We consider that some of the identified problems – a), d), e) and f), (above) indicate that the system should be radically revised at the earliest possible date and that, before doing this, those responsible should look at systems used in other countries in order to identify improvements that could be applied within the cultural, geographic and economic contexts of Albania (Recommendation 28).

There are also clear indications of the need for more paediatricians specialising in disabilities, and for further disability-related professional development for both general practitioners and already employed paediatricians (see Section 19).

Problems a) and c) make it important for NGOs, social workers attached to the local offices of the Social Insurance Institute, ADRF and national media to publicise the support system in a variety of non-stigmatising and accessible ways to increase uptake of eligible claimants. Social workers and NGO personnel should continue to support claimants through the process (Recommendation 29).

In relation to problem g), we consider that the present system is actually inhumane. Children with severe lifelong disabilities or life-threatening or shortening conditions should be certificated to that effect and should not be required to undergo annual examination at the tribunal (Recommendation 30). Thereafter the parent or guardian should request a person approved by the local KMCAP as reliable, e.g., the local doctor or nurse, director of the local school, social worker of the Social Insurance Institute, or a local NGO representative who knows the child and family, to sign and date an official form. The wording would confirm that the signatory had seen the child on a date within the last two weeks and that he/she was still alive. This form could then be presented at the tribunal without the need for the child to be present.

Some parents in several areas suggested that local doctors accepted or asked for fees to certificate a child's disability, this certificate being a necessary document to take to the KMCAP. A paediatrician involved in the central KMCAP was shocked that such an accusation should have been made and thought it very improbable that this was so. However, we have made Recommendation 90 in Section 19 that should protect both doctors and parents of children with disabilities from mutual misunderstanding.

For many families where there were previously two working parents or where a single parent worked while a child with a disability was at school, income dropped suddenly when a child left school. If there was no further occupation for the child, a parent, usually but not always the mother, then stayed at home to care for the child. Relatives supported some families financially or materially.

Section 13: Social services and social support at critical times

Social work is a relatively new profession in Albania, with the first cohort of four year graduates completing their courses in 1996 although there had been one year training programmes since 1993. Disability is a relatively minor part of their course although some social workers are employed in the Ministry of Labour and Social Affairs Residential and Day Development Centres and in Welfare Institutions of various kinds. They are also employed in some NGOs working in the field of disability, including those concerned with children with disabilities. Some work with Local Authorities, attached to the local offices of the Social Insurance Institute and we have already recommended, in Section 12, their continuing and increased role in relation to claimants of the Individual Disability Allowance. We also suggest that they should be involved in the sensitive identification of families in any data-gathering exercise (Recommendation 31) as outlined in Section 7.

We believe that they could also be very constructively involved in working with families with disabled children in other ways at critical times in their lives. As we described at the end of Section 9, these are; the time of diagnosis or realisation of disability in their child and the years immediately following that, the time of school entry or, more commonly, of not being accepted for school, when the young person with disabilities leaves school or child-related NGO services and when a parent dies or is no longer able to care for their child. Other times may be if the child becomes ill or requires hospital treatment or when there is a financial crisis in the family.

More isolated parents, who have not received early support, even if it is only a visit and encouragement, may become almost 'embattled', believing that they and their child are not only neglected by society but also actively rejected. They increasingly come to see themselves as the only people that can look after their child and may even reject offers of help from within the family. This is not a healthy situation for parents or child.

I cannot bear to talk about the early years – they were so terrible – I thought that we were the only family so afflicted. I had no-one to turn to, no-one. If the Centre had been there then, our family life would have been better.

(Mother of girl (18) with severe learning difficulties)

I knew no-one who had a child like mine. I was frightened, angry, sad and terribly alone – even my husband did not understand then. Sometimes I wanted to die.

(Mother of boy with profound and complex disabilities)

She was a normal beautiful baby then she became ill at age two with arthritis and by eight she was blind. She had so much pain . . . and I suffered with her.

(Mother of blind girl (13))

I felt very alone, as though this had only ever happened to me and my child. They only gave advice on health, not on anything else. So we had to learn by ourselves.

Mother of deaf boy (10)

We recommend that Social Workers should have a broad personally supportive role with families who have children with disabilities and particularly at critical periods of the child's life. (Recommendation 32). Social workers could be a source of practical advice, offer links to relevant parent associations, encourage parents to go out, offer counselling on personal issues, link parents to other professional help and, if necessary, advocate on their behalf. We also suggest that at any later stage, where a child is placed in a residential institution, a social worker should be appointed as a public guardian *pro bono* (for

their good). Such a role is not located within an institution but rather stands apart from it and acts only in the interest of their client whom they must visit about four times a year unannounced (Recommendation 33).

In Section 20 we note that there are no fully trained Occupational Therapists in Albania. This profession has responsibility in other countries for the choice and provision of mobility and other aids and of alterations to houses to facilitate the daily living of children and adults with disabilities. We suggest that Social Workers should, at least for the interim, assume this responsibility in relation to in-house aids and adaptations, while physiotherapists could assume a more technical advisory role in relation to mobility aids (Recommendation 34).

Section 14: Residential Development Centres & Day Centres

In Section 7 we identified that there were approximately 235 children with disabilities in the six Residential Developmental Centres and 113 in the five Day Centres under the management of the Ministry of Labour and Social Affairs that have children (Saranda currently has only adults) (see Appendix 4). Of these Centres, one Centre in Tirana is actually both a *weekly* Residential Centre and a Day Centre (which we have counted separately) and there are three locations that have both Residential and Day Centres. These 'double' facilities are, in two cases, within the same location and jointly managed, and in the third case rather more distant and with a currently unresolved management structure. One 'double' facility also includes the management of two residential facilities subsumed from an Italian NGO.

We have looked at the Special Schools for children with sensory disabilities with attached residential facilities under Section 17.

We have used the term 'approximate' to describe the numbers as there are minor variations from time to time. There is a further complication in many centres. Some young (or occasionally older) adults for whom there was neither any possibility of returning home for a variety of reasons (including absence of personal records from previous management regimes), nor of 'moving on', remained in the centres. Some of these children and adults have more severe disabilities. In Section 6 we discuss this issue and make a very urgent Recommendation, 14, about these adults, most of whom have lived through the dehumanising and degrading physical and emotional regimes that existed in the early 1990s, 1980s and before and whose development has been as much impeded by that as by their mental disabilities.

We would like to reaffirm our conviction that children and adults with severe, profound and complex disabilities have equal value with all other children and adults and must be seen as people who respond to love and stimulation, given time, patience, understanding and sufficient numbers of highly committed staff to establish close personal relationships with them. Their needs are best met, as with all people, within well-supported families or, if necessary, within family-like institutions.

Members of our team were able to visit all the Residential Development Centres and five of the seven Day Centres. We would like to say that it is evident in nearly all Centres, Residential and Day, that enormous work has gone into improving the facilities both by Albanian personnel employed by the Ministry and by international and local NGOs. The Albanian members of our team were familiar with the previous situation in these Institutions, and the international consultant had worked in other countries trying to end 'dehumanising' institutions. We were, therefore, able to appreciate the positive improvements and the efforts that it took to achieve them. The work began in the early 1990s and is still continuing. It has taken its toll on the health and energies of staff, although most have found the improvements a source of encouragement in their work. It cannot have been easy for Albanian staff, struggling with stresses in their own lives, to have their previous work criticised, overtly or by implication, by international personnel. Like parents who have earlier received no help, a minority of staff are either embattled or disaffected in relation to their work and it may be that a proportion of them are unsuited for the work in which they are engaged. Work of this kind is, or should be, based on a close, respectful, affectionate and developmental relationship with the children in their care. This view was overtly expressed by some Directors and other staff.

On the question of staffing, this is a critical issue, probably the most important of all. To me, although some skills and qualifications can help, what I look for is personnel with a good level of general education - at least completed Pedagogical or Academic High School - and above all I look for people with the emotional intelligence to form affectionate relationships with the clients and who recognise that this is really important.

(Director of a Residential Development Centre and a Day Centre)

Ah yes, personnel! Well, there have to be changes and I must start with myself. As a paediatrician I cared about the whole child but my main focus really was on whatever was wrong with a child. Now my focus must be on the children in my care as social beings. I look for this in other staff too, and I look for good interpersonal communication skills and for real commitment to children. It is so much more than 'only a job' when you work with these children.

(Director of a Residential Development Centre)

We consider that there is still a long way to go before the children in these Centres have the kind of situations that truly optimise their holistic development as envisaged in the UN Conventions on the Rights of the Child. Our view is shared by most Directors and other staff with whom we spoke. Most of our concerns are in relation to Residential Developmental Centres although there are some shared concerns that apply to both kinds of facilities. We were pleased to hear in the Ministry of Labour and Social Affairs that Quality Assurance Indicators are being developed that both the Ministry and the Centre staff themselves may use to evaluate their services. An additional safeguard for children, or adults, with disabilities in Residential Centres would be, as we suggested in Recommendation 33, the appointment of an external public guardian *pro bono* for each individual resident.

Before looking more closely at some of the positive developments and remaining concerns, the issue of residential institutionalisation for children with disabilities itself needs further brief examination. Where living within a child's own family is not possible – and we accept that this may be so in some cases – there may still be other cases where earlier intervention could have helped prevent institutionalisation. The Red Barnet report (2002: 6) suggests that disability in itself may be the cause of some of the 17% of children who have disabilities entering – and remaining in - state orphanages from infancy. They acknowledge that, for others, there may be more complex reasons. We would suggest that there are probably always other contributing reasons. Not least of these are *public* attitudes towards disability which colour the decisions of individual parents, and the entirely correct perception that it is extremely hard in Albanian society currently to bring up a child with a disability within a family as we have illustrated in Section 9.

Attempts at de-institutionalisation of children with disabilities, therefore, need to address both these aspects above. It is also necessary to undertake pre-emptive work with parents in persuading them to keep their children with disabilities and to advocate for alternative forms of care for children with disabilities such as adoption and fostering. We commend the work undertaken by the NGOs Association for the Support of Albania's Abandoned Babies (ASAAB) and ADRF in working with individual parents and with doctors to create a more positive environment for parents to consider how they might care for their child themselves (ADRF 2003). We recommend that this work continues and that it is seen as a priority (Recommendation 35). Bethany Christian Services, which have some babies and small children with disabilities in their care, have also been involved in work of this kind and favour both adoption and fostering of children with disabilities as alternatives to residential institutional care.

Fortunately Albania has less institutional care of children than some countries, but institutional care is never a really good solution for any child. Children with disabilities are in the weakest position to survive the experience. Although neither adoption nor fostering is easy, they are better solutions. We have had some successful international adoptions of children with disabilities. Sadly so far, Albanian parents do not want to adopt children

with disabilities and fostering is not yet approved by the Government. We could have organised a fostering programme within our own funds in 1997, and offered to do so, but our proposal was turned down.
(Director of Bethany Christian Services, Albania)

While both adoption and fostering of children with disabilities need long-term support and monitoring, we hope that, as Albanian society develops, both may become preferred options of care.

We have already said that some staff appeared not to value children (or adults) with more severe and complex disabilities, although some were affectionate towards them but still did not feel they had any potential for development.

Well, I suppose they are people, but what can you do with them? Nothing really! We need to work with younger abler people.
(Educator, Residential Development Centre)

Such attitudes arise from lack of knowledge of ways of working with people with more severe disabilities, and lack of conditions in which such work can be undertaken. We recommend strongly that all staff working with children with disabilities in all kinds of Centres, Special Schools and Special Classes undertake training that enables them to work appropriately and optimistically with children with more severe and complex disabilities (Recommendation 36).

Staffing levels were very significantly poorer in Centres than in Special Schools. If anything more than physical care is to be achieved with children with more severe disabilities, then staff to child ratios must be high enough to reflect this aspiration. Generally speaking, the greater the disability the more staff are needed in order to work in a developmental way with clients. Staff must also be self-motivated to work in such ways and to have their conditions of service planned to enable them to undertake more intensive contact with their clients. The practice of long working shifts on a smaller number of days may make sense to staff in relation to their home lives but it generally does not make for greater energy at work. We recommend that conditions of work be established in all Centres that enable staff to work appropriately and developmentally with the children in them. These conditions must be enhanced where there are children with more severe and complex conditions (Recommendation 37).

While residential institutions do continue, the quality of staff and of staff training are essential to children's positive experiences. We were very pleased indeed to hear about the collaborative training programme being developed by the Ministry of Labour and Social Affairs, its Centres, Vlora University and the NGO Association pour le Soutien d'Enfance en Detresse (ASED), Fribourg University and the Swiss Government. We spoke briefly with representatives of ASED and with the co-ordinating member of staff at Vlora University but were unable to examine the programme in detail. Our hope is that it will be in line with the broadly inclusive and developmental trends envisaged by the Albanian Government in relation to education as well as developing knowledge, skills and attitudes that are essential within the largely separate current environments of the Centres. It was evident that the Centres' staff members already involved in a pilot programme and who will mentor new entrants to the three year training programme are enthusiastic about it.

If a longer term view was taken in line with Recommendation 13, that educational / developmental programmes for children should become the responsibility of the Ministry of Education, then children remaining in Residential Centres for children with disabilities would actually leave the Centre daily to attend a mainstream or special school or special class. This was already anticipated in the case of a small number of individual children in Residential Developmental Centres, while the Directors of other Centres were prepared to consider this option, depending on their confidence that the education would be appropriate.

In principal it is good for a child living in an institution to get out and see something else, even if it is a special school. But inclusion would be better if it was well managed.

(Director of a Residential Developmental Centre)

As we mentioned both in this Section of the report and in Section 7, we found that many Centres had some adults as well as children - one Centre had an age range of 7 to 85 years, albeit with most in their late teens to early thirties. This situation resulted from a lack of adult provision. There is a need for separation of shared living accommodation of children and adults and of small children from much older children. However, our hope is that Residential Centres would ideally reduce the numbers of clients served and that provision in general would move wherever possible towards day provision with weekly provision as a first compromise choice. Internal structural division of larger institutions into smaller family-type groupings is also a positive compromise solution where a goal of smaller detached and more normal family-type homes is not attainable in the near future. This is actually being envisaged within one Residential Centre:

We will mainly have 'official' orphans here, many with quite severe disabilities, and when our structural alterations are complete we will have four living areas with a 'family' of children and staff in each so it will be a more normal context.

Director of a Residential Development Centre

As we have already indicated in Recommendation 14, we believe that, if new provision is to be developed for adults, it should be of a family kind and size. We also think that adults who have lived together over some years should be grouped together in any re-housing exercise. Those who have retained any family or friendship connections should be located near them but we also think that those who have grown up in children's institutions should be located within easy reach of these institutions. People with severe disabilities *do* form attachments, both with staff and with remaining younger clients, and it is cruel to break these emotional bonds for management convenience.

We welcome the improvement of record keeping and of increased attempts to maintain family links in both Residential and Day Centres. Some staff spoke of difficulties they experienced in relating positively with parents or family members who functioned at 'very low social levels' and who may not have behaved well towards their child with disabilities in the past. While we do understand this, part of professionalism is to be able to continue to relate to people who are important to the children in their care, as are all parents, even those who are perceived to be 'bad'. We suggest that the development of good parent-staff relationships should be a focus of staff development and that Centres' (and Schools') practical arrangements for receiving parents should reflect a welcoming approach (Recommendation 38). The development of contracts with families whose children attend Centres will probably have some benefits but they do require to be implemented with humanity. We suggest that this interesting development might be an appropriate research topic for a final year or post-graduate social work or psychology student (Recommendation 39).

As we have mentioned, one Residential Development Centre appears to have been designated for the reception of 'official' orphans from both Residential Development Centres and (possibly) Social Welfare Institutions. If, however, the numbers given in the Red Barnet (2002) report are correct at 17% of the total State orphanages' population, or 79 children (see Appendix 4), it seems that this may not be possible, given the particular Residential Development Centre's capacity of 26 and its current population of 17. It may be *either* that the other children with disabilities are under the normal six year entry age for Residential Development Centres *or* that they have only mild disabilities and can cope with their existing situation. However, we recommend strongly that the situation of remaining children with disabilities of all ages within State and private/NGO orphanages should be clarified by the Ministry of Labour and Social Affairs and appropriate plans developed for them that lead to family or family-type care and inclusion (Recommendation 40).

While larger Residential Development Centres do continue to exist, the integration of their residents' lives with that of the surrounding community remains a challenge that is not easily met. We are aware that the isolated functioning of Centres has been a subject of criticism in the past and we understand that it is much easier to criticise than it is to find workable solutions.

My concerns are about structuring work so that institutions are better linked to the community. It is not so simple as taking handicapped children for a walk in the local park. We could run an integrated play centre for the community where children without disabilities could also come, or we could have activities for local families here to break down the barriers

(Director of a Residential Development Centre)

Several Centres spoke of local and national dignitaries calling on Centres on special occasions and of how some families brought food and clothing for residents. The goodwill behind such gestures must not be scorned but it is hoped that both neighbouring communities and prominent people could be encouraged to participate in more inclusive and less 'patronising' ways. SOS Kinderdorf villages in some other countries send their children to local schools, including their pupils with special needs. Local children come in to play in the villages. Staff also encourage carefully monitored families or adults from the local community to develop long-term and regular contacts with their children, sometimes involving outings and shared holidays, personal birthday and Christmas or Eid cards and presents.

Bethany Christian Services' programme in which young pregnant women were accommodated within Albanian 'foster' families show that there is goodwill in the general population. The Centre Director quoted above also had some constructive ideas that involved 'internal inclusion' – opening the Centre to neighbours. Centre residents should, of course, be welcomed in their neighbourhood and beyond and local authorities should be actively involved with Centres in seeking inclusive and 'normal' ways of ensuring this (Recommendation 41). Residents and accompanying staff should have a small budget to ease their local participation and not have to rely on always being objects of charity from others (Recommendation 42).

We were pleased that most dormitories were now much brighter and fresher than in past years, although some were still unacceptably over-crowded and several were far too cold during our February visits for more frail and less mobile residents. In one Centre the heating boiler had been broken for some time and residents had been sent to bed to keep warm. We thought that this was unacceptable, as was the continuing use of rags rather than disposable nappies with incontinent residents in one Centre. We understood that most Residential Centres had received many donations of toys and more personal items yet in dormitories there was little if any sign of personal possessions. We appreciate that managing personal possessions is often the subject of disagreements between clients but learning about 'mine' and 'yours' is an important developmental task for clients and staff to address. We recommend that material and humane standards in Centres continue to be both internally evaluated and subject to external inspection and support (Recommendation 43).

Two Centres spoke of difficulties in relation to medical practitioner services for their Centres' residents. We think that institutionalised people have the same right to good medical attention as other Albanian citizens and have made a Recommendation, 86, to this effect in Section 19.

We welcome also the introduction in some Centres of Individual Educational Plans (IEPs). There is always a risk, as with new forms of record keeping, that IEPs either become an obsession or that they vanish into a cupboard shortly after they are developed and never become fully functional. We recommend that Centres and Schools find ways of keeping and updating records and IEPs and of implementing IEPs that enable them to be useful but not an unacceptable burden that erodes time that

should be spent by staff in working with the children with disabilities in their care. We also think that IEPs in Day Centres (and in schools) should be shared with families in terms of planning and implementation (Recommendation 44).

We shared the concerns of staff who were frustrated in their attempts to develop viable workshop activities, particularly of possible commercial interest, and would hope that they might benefit if an NGO and/or Donor adopts our relevant Recommendation 26 in Section 11.

Section 15: Education

This Section looks at the 'mainstream' education system in general to examine:

- ❖ how it functioned in relation to children with disabilities (or special needs according to the new *Normative Dispositions* terminology) before the recent growing trend towards inclusive schools,
- ❖ what the issues facing the education system currently are, and
- ❖ how these issues may impact on the development of inclusive schools.

Our discussion focuses primarily on the kindergartens and the eight-year basic education schools (both lower Grades 1-4 cycle and upper Grades 5 -8 cycle). The apparent total lack of access to special or mainstream vocational education for pupils with special needs, allied to the very high unemployment rates and lack of specialist workshops, is a very serious concern indeed for children and young people with disabilities and their families. This was also a serious concern of the Ministry of Education representative with whom we held discussions. It reflects the overall depressing situation facing most young people in Albania today. However, because of our remit being focussed on the child population we have restricted ourselves to two Recommendations, 26 and 27, in this area in Section 11. Able blind pupils and a very small number of mobile pupils with physical disabilities do proceed to Secondary Schools and from there they may go on to University.

Attendance at Kindergarten is not compulsory and about 35% of children attend them in cities and larger towns, significantly less in villages (Musai 1992).

It is known that significant numbers of children between ages 6 and 14 who are eligible to attend what is, by law, *compulsory* eight year education do **not**, in fact, attend school although reliable statistics in this respect are not available. This is clearly a major concern to the Albanian Government which is seeking to comply with the UN Convention on the Rights of the Child, Article 28, on the right to education and its campaign for 'Education for All'. The Government is also seeking to bring Albania closer to European Community standards. Children's right to education, often a right to ten or twelve years of education, and required attendance at school, are clear requirements for countries seeking to enter the EC.

Albania is facing a substantial challenge in bringing all children at least into eight year compulsory education. The children outside education in Albania are diverse:

- ❖ children from very distant off-the-road settlements in the mountains of the north-east or the inland areas of the south who simply cannot reach a school,
- ❖ other similarly placed children may be on a road of some kind but still lack transport and be too distant from school to walk there and back on a daily basis,
- ❖ children (with or without disabilities) who may have attended school for a period of time then 'dropped out'
- ❖ Roma children whose families may not be acculturated to formal educational processes or who are still itinerant or not fully settled,
- ❖ children whose families have migrated from less developed areas to Tirana or other cities and whose parents may either not yet have enrolled them or who cannot find a school with a vacancy,
- ❖ children who work at home or elsewhere,
- ❖ children who are on the streets of towns,
- ❖ children who are in hospital or ill at home,
- ❖ children who have emigrated seasonally with siblings or parents and, finally,
- ❖ children with varying levels of disabilities.

This list is not exhaustive and many children will actually come into several categories as the quotation below illustrates. This mother was unconvinced of the value of education for any child although her son with physical disabilities was now attending an NGO centre within a Roma community with which she was pleased.

He was born like this. I was hoping that when he grew up he would be better, but nothing changed. I haven't sent him to school. Why is school necessary for him? Even my other children who have no problems - I haven't sent them to school. I need him to work, to come with me and help me, but he is not able for that, he needs somebody to be with him, but he does help me a bit at home.

(Roma mother of boy (12) with lower limb impairments and restricted mobility)

There are other challenges than simply numbers of children still to bring in to education. The questions of how and to where they will be brought in, once tracked down, immediately raise very large costs. School transport is a major budgetary item for any education authority that pays for it or subsidises it. It will certainly be necessary for all children in some areas, for very many younger children in more areas, and for all children with disabilities living outside town across Albania. It is likely that some children whose families continue to live in isolated areas will need to have at least weekly accommodation at or near school and, again, this would apply to some children with disabilities. Migration has emptied or greatly reduced numbers in some areas' schools and filled the schools in Tirana, other towns and the central area of Albania well beyond capacity. A capital-heavy building programme seems to be necessary to create new schools and to renovate old ones in the more heavily populated areas and to build new schools or provide transport from isolated areas where there are currently no schools, while still maintaining existing rural schools for the remaining population to help prevent further migration.

In addition to the pressures brought about by 'Education for All', Albanian school curricula and teaching methodology are undergoing development, producing more work for teachers. Such changes, however important, are stressful and can bring about teacher fatigue and disaffection. A further factor may be that, with society and individual families under pressure of poverty and poor housing, family relationships and parental discipline of children may also suffer, producing more behavioural disruption and troubled children into schools. Under a recent pilot programme some schools in Tirana have now been allocated psychologists to help resolve some of these problems. Even in more distant areas there are signs of pupil unrest.

Our teachers are less worried about having one or two slower or slightly disabled children than they are about the children who are rude or difficult to manage. We see more of this now.

(Deputy Director of school involved in inclusion project)

While our research specification did not cover children with social, emotional and behavioural difficulties, we were conscious of their presence and for this reason felt further investigation would be useful (see Section 1. Recommendation 1). We were concerned not only for children's well-being, but also for the smooth running of schools. Further, pressures produced by other groups of children could impact negatively on schools' and individual teachers' efforts and willingness to include children with disabilities. We recommend that children with disabilities are considered at every stage of the national efforts to achieve 'Education for All' (Recommendation 45)

We found some evidence of how schools already responded to children with disabilities in descriptions from parents, teachers and written accounts of the antecedents to the current drive towards greater inclusion, notably in ADRF – Nano's (2002: 50 *et seq.*) report, *Albanian Schools in the Integration Process*. Some key points emerged. Even before specific projects focussing on integration/inclusion started,

there were many children with mild disabilities, most often specific literacy and generalised learning difficulties, speech and language impairments and slight mobility problems. More significant visual, hearing, physical and health disabilities were rare.

In one NGO local identification and inclusion project that we visited, the local organiser reported that, of 110 children with disabilities who were in the local mainstream school (mainly with mild disabilities but registered as eligible to receive first level disability benefit), about 75 to 80 had already been enrolled in the school prior to the beginning of the project. A further 30-35 had been brought in as a result of the NGO's advocacy and partnership with the local Education Authority. However, 160 children registered as disabled were still *not* in school at all and 76 were in the local special school. This district was already pro-inclusion, as are some in Tirana, but other districts are reported to be less favourably inclined. There is evidently still much work to be done in all areas but especially in those that have not turned their minds to this challenge.

We also found evidence of other children with disabilities who had either been refused entry, or whose parents had to fight for their child to be admitted, or who had been accepted then sent away.

I enrolled my son in our local school. He is a clever boy but he has a condition that makes him very small and he has some other physical problems although he can walk. He was pleased to be there with his friends. But then the school asked me to remove him as they did not want to be responsible for him. He does not suit the special school because they are slow and he is not, So he stays at home, sadly.

(Father of boy (8) with congenital physical disabilities)

There aren't the right conditions in the school or in the classroom for my daughter who uses a wheelchair. There were no ramps or space. The teacher worked with her for about one and a half years without any specific program and without registering her like the other children in the school documentation. After that the school could not take care of her so she stayed at home. Now she is only able to read slowly, letter by letter and she goes to physiotherapy once a week. - I pay for it. Maybe it would be good if the school sent a teacher home to help her.

(Mother of girl (now 16) who had meningitis at age six months and is diplegic, but of normal intelligence)

The family came to us with their boy and all the documentation including a letter from his previous teacher in the local school. Actually our assessment and the psychiatrist's was that, although he is not so clever, he is really of normal intelligence so we said he should stay in the local school. But the teacher had persuaded the parents that he was better suited to special school so in the end he came to us and is quite happy.

(Director of Special School about boy aged 9)

Our meeting with ADRF representatives confirmed that there are physical access problems to many schools and a lack of family or school transport. However, ADRF also confirmed that many schools and teachers simply refused to take some children who did not 'fit' the 'standard pupil' requirement. However, the last example above is particularly worrying as it suggests that a single class teacher had the right to send a child away, or persuade parents that a child was not 'suited' to school. We recommend that the Ministry of Education ensure that each Local Authority appoints a Director of Educational Support who will have responsibility for pupils with special needs resident within the Authority, for Special or Resource classes in Mainstream Schools and their teachers (see Section 16), and, jointly with the Ministry of Education, for Special Schools located within the Authority (Section 17) to ensure that all pupils with special needs within any authority receive appropriately supported education (Recommendation 46).

We also recommend that children with disabilities or medical conditions should only be refused entry to their local school, or 'sent away' from any school in which they are already enrolled, if the Director of the School has sent all documentation to the Local Authority Director of Educational Support, consulted with her/him, and been given consent for the action (Recommendation 47). We are aware that the *Normative Dispositions* (Albanian Government 2002a) appear to permit children of 'limited ability' to leave school 'when it is judged that they are not benefiting from these institutions or when there are more effective form or possibilities' and that schools are urged to try and keep children in school. The international consultant, in particular, felt that the possibility of 'legal' dropping out might be used to undermine the concept of 'Education for All' and to disguise insufficient teacher effort with pupils who find it harder to learn.

Section 16: Inclusive schools

Our meeting with the senior Ministry of Education official responsible for 8 year compulsory education and special education confirmed that Albania's educational policy was to move towards more inclusive education. However, if it became apparent that more special provision was needed, then this would be undertaken although the overall trend would remain inclusive.

What has come to be called the 'inclusion debate', or, in some countries, the 'integration debate' has proceeded slowly over the last 25 years, in the US, Canada and most countries in Europe (O'Hanlon 1993). Many parents, professional pressure groups and human rights organisations are strongly in favour of *all* children being educated *together*. This found full expression in the Salamanca Statement (UNESCO, 1994). The inclusive view identifies 'difference' of any kind as a feature of all adults and children, albeit to varying degrees, that must be accepted, valued and from which all can learn in a positive way.

A moderated view is now that inclusion or integration is not something that a child with special needs must achieve by adapting to the norms of the peer majority. **Inclusion is, rather, something that education authorities and mainstream schools must work towards by ensuring that there are sufficient support services, well-trained teachers and other staff and, above all, a whole-school ethos of welcome and inclusion.** Together, these conditions within a school can make greater inclusion of children with disabilities - and indeed children of other minorities such as Roma children and children with social, emotional and behavioural needs - a positive experience for all. There is also increasingly a view that some specialist provision may be necessary, for some children, for at least some of their education careers. However, it is thought that these Special Schools and classes also have a responsibility to ensure that their way of working does not cut their pupils off from the wider peer society and local community nor from optimised opportunities for their post-school lives.

An adaptation of Booth's (1998) definition of inclusion sums up what many parents, teachers and children themselves currently see as inclusive education:

Inclusive education is the process of increasing the participation of all pupils in the curricula, cultures and communities of neighbourhood mainstream schools which value diversity, in such ways that they learn effectively in a safe and happy environment.

Parents in Albania, as parents across the world, want their children with disabilities educated near home and to have some school contact with siblings and neighbourhood peers, even if, for some with more severe disabilities, some of their education is provided within a separate context. It is important that they have an individualised educational programme (IEP) to help them learn and that recognises ability and potential as well as difficulties, and that is planned with families. They want the school to be accessible and practical help to be available as needed. Parents want their children to be safe, to be treated with respect by all staff and peers, and to be free from any bullying or stigmatisation. They hope that their children will find companionship and friendship in school.

It could be thought that Albania might be at a disadvantage, starting as it does from behind many other European countries in terms of its basic 'Education for All' and with very limited financial resources. However, this is not necessarily so as we have already seen in relation to Residential Developmental Centres. Where a country has developed relatively little special separate provision, there is less to undo and change, although it is still hard, it is on a relatively small scale. Countries that invested heavily in many large segregated institutions and schools have found the road to inclusion very much harder.

Albania has another great advantage – it may learn from the numerous mistakes of other countries that have preceded them on the road to inclusion!

There are some powerful arguments for retaining some specialist provision. In the 1996 *UNESCO Survey on Special Needs Education Law* which examined the legal entitlements of children with special educational needs and levels of inclusion across 52 countries of the world, **no** country had achieved total inclusion in the absolute sense of all age peers being educated together in local mainstream provision. Even relatively rich and educationally developed countries where all children were in education had generally stopped short of total inclusion. Reasons for this were various:

- ❖ Some parents or children wanted special education, believing that it met children's special needs better and/or that their children were 'safer' and/or 'happier' in special provision. Parents' views may not always be correct but they have right to safeguard what they feel are the interests of their children.
- ❖ Families, specialist teachers and some children, in particular with sensory disabilities, argued that children with sensory impairments needed some children with the same disability in their school peer group, in order to develop a strong sense of identity and personal worth.
- ❖ Some governments endorsed this view, also arguing that only by having special schools or special classes could sufficient expertise be gathered together to meet all the diverse needs of children in an economically viable way.
- ❖ In a few cases, parents of *other* children or education authorities argued that it might be against the interests of children if those with special needs of a disruptive kind, such as some forms of attention deficit disorder or aggressive behaviours, were included.
- ❖ Professionals and some parents advised that education in mainstream classes could be positively harmful to some children, being too noisy, too confusing and too large for them to comprehend and to learn in.

This gap between international guidance and the rhetoric of total inclusion on one hand and the reality of less than total inclusion on the other can be seen in countries where *all* children go to schools but around one, or at most two, per cent of their children attend special provision of some kind. Most of these countries argue, with reason in the Consultants' view, that there are indeed some children who would not benefit from being in mainstream classes all of the time and who need access to special environments for at least some of these activities. We discuss in the next section how Albania may weigh up the factors for its future planning of special provision.

With a number of successful pilot inclusion projects already undertaken (ADRF – Nano 2002) and with the approval of the *Normative Dispositions for Pre-university Education, Article 57: The Education of Pupils with Special needs* (Albanian Government September 2002a), Albania has already made very substantial moves in the right direction. Under the Dispositions, schools are encouraged to move towards including more pupils with disabilities in their area. In schools that do so, teachers with pupils with disabilities in their class have a right to extra pay, or extra non-teaching hours or a reduced number of pupils in class. Schools may also undertake outreach teaching to pupils with very severe disabilities or medical conditions in their homes, and they may seek permission to open special classes. Several schools that we visited have made great strides towards being an inclusive school, as the profile of the school below shows.

Profile of rural/small town inclusive school P

School P is located in a small town but also has a wide rural catchment area and has an active and enthusiastic Director. It has 800 pupils in 30 classes, with two shifts. It is part of a large social and educational project in which an NGO, UNICEF and the local Education Authority are partners. The school carried out a search to identify children with disabilities not in school and to open a record of their details. This school already had many children with mild disabilities on its register, although some were struggling or failing to keep up with their peers. Nine 'new' children were identified, seven came in to school and two with very severe and complex disabilities are now educated at home. A volunteer teacher from the school who receives extra pay through the Project funding provides this service.

The school has established a special class for five children with combined physical and mental disabilities but the children share social and recreational opportunities with the other children. IEPs are in use but individualisation is only planned as necessary. Training was provided by the NGO representative, a highly experienced teacher of children with disabilities.

School P already had an overall positive ethos but staff found that their additional efforts with children with disabilities and their families seemed to have a positive effect on all their home-school relationships. The Education Authority is proud of the school because it is not only making strides in inclusion, it is also top of the Maths attainments in the district, showing that working hard with less able children does not disadvantage other pupils. The Director now mentors other schools starting out on the road to greater inclusion

Factors that the Education Authority thought were important in School P's success were:

- The school already had a positive ethos,
- The Director is committed to inclusive education
- The school's teachers have high expectations of all pupils, but individualise programmes and activities wherever it is in any child's interests
- School staff had training and encouragement
- The Project helped school staff from other involved schools to meet and share good practice and also funded the additional payments, or shorter hours, or reduced class size offered within the *Normative Dispositions* that the Government cannot currently afford to pay.
- The key innovators were people who were already respected in the area
- Although the school had a very large catchment area, many people knew each other, including the NGO's organisers and the families of children with special needs.

We met Directors, Deputies and teachers from the Project area who identified benefits arising from the Inclusion Project:

- ❖ the use of IEPs and the planning necessary to start them showed teachers that they had not known children's real 'starting levels' in all areas before,
- ❖ the realisation that knowing pupils deeply as individuals helped teachers to plan more meaningful educational programmes, both for individuals and for larger groups, and for very able pupils as well as for very slow pupils,

- ❖ there was a widespread feeling that the community was somehow more complete because all or nearly its children were being educated in one school,
- ❖ a more positive ethos was generated in the schools because of the collective efforts being made,
- ❖ teachers felt a sense of genuine success after they struggled to enable a child with special needs to succeed and to feel part of the class,
- ❖ being able to provide education in their family homes for children who were very fragile or seriously ill was a bonus for both child and parents,
- ❖ Parents of included children were pleased that their children were accepted within the school
- ❖ Teachers up to Grade 4 felt that their additional work was appreciated because the Project was able to fund one of three choices; fewer pupils, more non-teaching time or additional payment

The profile of School P. and the points above link with some of the positive findings from the ADRF – Nano report. However, problems were also identified in the ADRF-Nano report, by the school staff that we met and by the Project co-ordinators. We list below difficulties that we think have implications for the wider development of inclusive schools in Albania.

- ❖ Many teachers still felt very ‘tied’ to the curriculum and to whole class teaching.
- ❖ Where a child’s difficulties were more severe it was harder to include him/her, even with an IEP.
- ❖ Children whose programme was mainly based on an IEP no longer seemed as though they were part of the class.
- ❖ From Grade 5 peer social relationships were not so supportive – social maturity gaps widened.
- ❖ There was some confusion among teachers about whether children were allowed to continue progressing up the school after their fourth year even if they did not attain a ‘pass’ standard in their core curriculum subjects. Schools within the Project did retain ‘failing’ pupils but they were aware that schools in other areas either requested parents to remove their children or referred them to special school if there was one in the area. (The *Normative Dispositions* do in fact make it clear that progression is assured, regardless of assessment outcomes but this was a widespread confusion. This supportive clause in the *Normative Dispositions* was rather offset by the clause that allows pupils to leave school before age 14 if their learning does not seem to be progressing and if their parents request this.)
- ❖ Inclusion becomes mutually more problematic for pupils *and* teachers from Grade 5 onwards with the introduction of more subjects and more teachers but there were not enough funds to offer Grade 5 – 8 teachers the options set out in the *Normative Dispositions* which seemed unfair to the teachers concerned.
- ❖ Resistant teacher colleagues were seen as the most challenging problem of all, particularly colleagues who were more subject-centred specialists from Grade 5 onwards rather than child-centred, but even some class teachers in the earlier classes found it too much trouble to differentiate the curriculum.
- ❖ All staff involved expressed a need for themselves and for their colleagues to have further staff development. They considered that current initial teacher training at all levels and post-qualification training in meeting special needs was totally inadequate.
- ❖ Teachers were interested in the concept of each school having a supernumerary ‘support’ or ‘resource’ teacher who would have more specialist knowledge and skills and would support and advise other teachers.
- ❖ Many children came into school at six or seven with very little basic communication or social skills and most had not attended kindergarten. There was a need for more early intervention.
- ❖ Teachers now appreciated that good record-keeping helped planning in education and was essential if IEPs were to work.
- ❖ Some teachers found working in partnership very difficult with parents who themselves functioned at a low cognitive and socio-economic level.

- ❖ Teachers found some special needs harder to cope with than others, e.g. deafness

We visited, rather briefly, another school in a very different location which was also working hard to be inclusive of its pupils who had disabilities but which also had many pupils with social needs.

Profile of City inclusive school S.C.

The school is in a poor area with many needy families and 23 children in the care of social welfare institutions. The school has a special parent-mentor programme for these children so that each of them has a teacher who develops a closer relationship with the child and sees him/her each day. The Director said *'We are very conscious of all our children's needs'*. They also have 14 children with a variety of disabilities. None of the teachers gets any of the three options offered in the *Normative Dispositions* because this school does not have Project funds to support the options and the Ministry cannot yet resource this either. The Director would like to pay the teachers who work well with the children with disabilities but there is another problem, *'And in Grade 5 onwards, a class might have five or seven teachers – are they all to get money?'*

A Grade 6 teacher in the school described one of the pupils in her register class who has physical and mental disabilities, a loud voice, does not relate well with other children and was sometimes rude to his previous teacher. He had struggled through Grades 1-4 and his mother came into the school to try and advise the various Grade 5 teachers about how he was and how he could be helped. Grade 5 was difficult. His current Grade 6 register teacher has written an IEP for him and keeps him very busy and relatively successful. She finds it hard work. Asked why she worked hard for the boy's inclusion, she said, *'I felt sad for him, I could see it was not going well before. Then his mother came to speak to me and she moved me with her concern for her son. She asked me, "How would you feel if he were your son?" and I realised that I would want the teachers to be kind and work hard with him, so I do just that.'* Asked what help or advice she had received to help her teach him, she replied, *'Well, only from his mother, she knows him so well, and now I know her well, so we work together.'* He had been in the school for four years – he had first been registered in Grade 3. In previous years he had been teased, but the teacher had spoken with the other children in his class and explained the boy's difficulties. *'Now they understand and they are kinder. It helps that they see I am patient with him and that I like him, they learn from that.'* This teacher would have liked someone in the school with more knowledge of special needs to turn to for advice.

We have already recommended (Section 15, Recommendation 46) that the Ministry of Education ensure that each Local Authority appoints a Director for Special Needs who will have responsibility for pupils with special needs resident within the Authority, for Special or Resource classes in Mainstream Schools and their teachers and, jointly with the Ministry of Education, for Special Schools located within the Authority to ensure that all pupils with special needs within any authority receive appropriately supported education. We believe that more needs to be done to support the work of Directors of Schools to develop inclusion further. Research in inclusive education points clearly to the vital importance of positive committed leadership if a school is going to be effective in teaching its pupils, maintain high standards and develop inclusion. We would therefore suggest that both the Local Authority Directors of Special Needs and Directors of Schools be prioritised for professional development in inclusion (Recommendation 48).

We have made recommendations in Section 20 in relation to teacher roles and teacher development, including the development of new roles of Resource Teachers and Specialist Resource Teachers (they would have a higher qualification than existing special or mainstream Teachers and should *not* be confused with Educators or Supportive Teachers) and about the establishment of a National Educational Support Centre in Tirana.

We also recommend that each larger Local Authority establish a District or Municipality Education Support Centre to act as; a display centre for teaching and learning resources, a base for in-service activities and a base for any peripatetic support staff. Groups of smaller neighbouring Authorities might develop a shared Support Centre (Recommendation 49).

There is a serious risk that the *Normative Dispositions* (Albanian Government 2002a) may fall into disrepute with teachers and parents if the Ministry of Education is unable to honour its commitment to giving one of the three 'relieving' Options in the reasonably near future to teachers who implement inclusion. We recommend that the Ministry of Education be asked to set a time-scale for their implementation, if need be reducing the Option benefits initially to facilitate earlier part-implementation. There should also be clarification of how the Options would apply to teachers in the upper cycle of 8-year schools (Recommendation 50)

Larger, or smaller but isolated schools, and possibly pairs of smaller neighbouring schools, should establish a Resource Base that would have multiple roles. Some children with mild and moderate disabilities could be withdrawn there for additional help from the Resource Teacher, as could very able pupils who need extension studies. The Resource Base might also be where computers, once affordable, could be located and other electronic equipment (Recommendation 51).

We have considered the concept of Special Classes within 8 year schools carefully. We recommend that they should only be established for children with severe and complex mental disabilities as they come into schools, not as currently, for pupils with *moderate* to severe disabilities. Special Classes would be authorised by the Ministry of Education but the Local Authority would have a partnership role in their day to day running. Staffing would include a Specialist Resource Teacher and trained educators at a level that reflected the number of children in the Class and their degrees of disability. Children with mild or moderate disabilities should be within mainstream classes with IEPs and some support in class and in the Resource Base (Recommendation 52).

Children with physical and health-related disabilities but without mental disabilities or with only mild to moderate mental disabilities should be included as far as possible in mainstream classes. Those who are not able to attend school should receive some home-based education (Recommendation 53). There is a need to establish a programme of physical access adaptations to at least one school in each area initially. Where a child with a physical disability has to go to a school that is not his/her local school, the Education Authority should subsidise the costs of transport (Recommendation 54).

Resource Room, Special Class provision and good physical access should be integral to the planning and building of all new 8 year schools (Recommendation 55).

Although we accept that some teaching of children with severe mental disabilities may, at least for the foreseeable future in Albania, need to be undertaken in small separate groups for some or most of the time, we consider that it is very important that no child should spend all of his or her time in a Special Class or in a Resource Base and that, whenever possible, he or she should spend optimal time with mainstream classes, including being registered with age peers in a mainstream class (Recommendation 56).

Section 17: Special classes and schools

There are eight special schools, including two residential schools, one for Deaf and Partially Hearing Children and one for Blind and Visually Impaired Children. The other six daily special schools are broadly for children who have ‘special needs’ usually including some degree of mental disability from mild/moderate to severe, and some children with additional other disabilities such as mild sensory or physical disabilities. There are also four areas that have special classes either free-standing or attached to mainstream 8-year schools. These special classes are, again, predominantly for children with moderate ‘special needs’. These educational establishments together educated a total of 794 pupils at the time of our research.

Our research team visited all but one of the schools, and also visited one of the locations with special classes. This area had two classes that were attached to large 8-year basic schools in small/medium towns. While the Special Schools for Children with Special Needs in Tirana and Korce have good material conditions, the school in Vlore is unacceptably over-crowded. In Korce, school was part-time (mornings only) to economise on the budget. Parents found this unacceptable. In Elbasan, the school was in an historic building, elegant but not very practical in some respects. Shkodra had an integral gymnasium/hall, as did Korce.

Activities in class seemed to be very traditional ‘sitting and learning’, usually paper and pencil exercises in a receptive model of learning (knowledge passed directly from teacher to pupil). It is not possible on the basis of one visit to evaluate the education generally. However, in some classrooms there was little room for more active or group learning which can motivate pupils who find it harder to learn. Teachers seemed to be committed to their work and, in terms of staffing ratios and hours of work, had conditions that should enable productive work.

The Special Schools for children with special needs really only serve the areas near where they were located and some seemed to be quite full. A small number of children came from a slightly greater distance. In these cases, parents nearly always brought children, a few older children walked and a very small number came by bus, including the buses that sometimes bring other children in from villages to the town schools. It is hard to imagine how some pupils will come to school without the provision of transport – we see this as a priority (Recommendation 57). As we mentioned in the previous section, although the Ministry of Education and the Albanian Government are committed to move the educational system towards inclusive policies and practices, they have also said that they would create more special provision, if necessary.

Special Schools are administered directly by the Ministry of Education and appear to have relatively little contact with the Local Authorities whose children are enrolled in their schools although some Special and Mainstream Schools had made positive links to which we refer later. Teachers and Educators (assistant teachers usually with a lower qualification than Teachers) have not, for instance, been included in the staff development that mainstream colleagues have been undertaking in relation to the curriculum and teaching methodology. Such training would undoubtedly have been useful and stimulating. Nor have they (with the exception of the Depute Director of the School for Deaf Children) been included in the ASED-Vlora University training programme for educators in the Ministry of Labour and Social Affairs Residential Developmental and Day Centres. This would also have been highly relevant. We make a recommendation in relation to the sharing of training opportunities across management and sometimes across professional divides in Section 20. Meantime it is sufficient to say that all special school staff and Directors, and teachers working with children with disabilities in mainstream schools, recognised some of their training needs. These included: adequate differentiation, ability to assess the attainments and specific problems of children, effective

development and implementation of IEPs, knowledge of how to work with pupils who have sensory impairments and effective ways of grouping pupils for work.

The Ministry of Education (Memo from Mr Eduard Osman to Minister of Education Luan Memush, dated 5 May 2002) also identified areas requiring development and already proposed developments in special schools and classes:

- ❖ There are no quality indicators for special schools,
- ❖ The curriculum did not include newer subject areas especially relevant for pupils in special provision, notably life skills and therapeutic/rehabilitative subjects,
- ❖ There was a need to revise written and other resources from the national programmes to meet individual needs,
- ❖ Staff development on special schools and classes had, over the previous years, largely been carried out through Donors and NGOs. This had now largely ceased so there were plans to set up a working group to look at this issue.
- ❖ It was planned that each school would have a counselling centre with its own psychologist and social worker attached.
- ❖ Schools that had previously been known as schools for children with mild retardation would now be known as schools for children with special needs.
- ❖ Teachers employed before the year 2000 received a pay supplement – more recent employees should also receive this.
- ❖ It was important only to recruit the best teachers.
- ❖ Ensuring and preparing for young people's societal inclusion after school should be prioritised in schools.
- ❖ Good basic physical conditions should be established in the schools, facilities for sport and PE and transport.

We hope that our Recommendation 46 in Section 15, that the Ministry of Education ensure that each Local Authority appoints a Director for Special Needs, will be implemented. Such posts already exist in Elbasan and in Korce. The Director of Special Needs would have responsibility for pupils with special needs resident within the Authority, for Special Classes and Resource Bases in Mainstream Schools and their teachers and, jointly with the Ministry of Education, for Special Schools for children with special needs located within the Authority. Some Local Authorities have already made such appointments and have found them very useful. Links between mainstream schools and Special Schools, which we were very pleased to hear some schools have already made under their own initiative, are important steps towards greater inclusion. Some of the links were related to sport, others to concerts or local celebrations. Other more curricular links should also be possible. We recommend that Special Schools seek partner mainstream schools (and that mainstream schools seek partner Special Schools) to explore a range of links, some of which could relate to sport and recreation and aesthetic subjects, but that might also involve project work and curricular co-operation (Recommendation 58).

We will now look at special schools under the sub-headings of Schools for Children with Special Needs, Special Schools for Blind Children and for Deaf Children and New Units for Children with Autism and for Children with Specific Language Disabilities.

Schools for Children with Special Needs

As well as visiting five of the six special schools for children with special needs, we also met some parents of past or present pupils from three of the six schools and some parents whose children had been considered too severely disabled to be admitted. We met pupils in the schools and former pupils in their homes and in NGO Centres.

I liked my school and I liked my teachers. Sometimes I wish I was back there.
(Boy (18) with combined moderate physical and mental disabilities)

He has cerebral palsy, He doesn't walk or talk but they say he probably has average intelligence from the way he responds to things, He sign 'yes and 'no' and uses many other signs that we understand. But they would not accept him at the special school. I thought they would not but I was still unhappy about it. I can see that he is bored sometimes at home. There should be a school for him and ways to help him.
(Mother of child (8) with cerebral palsy)

I like sewing and painting and making things. They're better than reading and writing. I'd like a job sewing but there aren't jobs now,
(Girl (12) with mild mental disabilities)

I'm not sure that she got a lot from school. They tried and tried to teach her to read and write and do sums but she couldn't. What she really needed was to learn to dress herself and care for herself and to do some simple tasks to tidy up. But she didn't get any of that at school – I taught her that at home. But I had to beg the Director to accept her so I could not complain.
(Mother of girl with Down's Syndrome, now 22)

If only there were some jobs they could work towards but there aren't. So where is school taking them? He could work but I know he won't. Meantime I'm glad he is there and has some friends. He can read a bit and write and he's a nice boy.
(Father of boy with mild combined disabilities)

I like everything – well, sport, anyway. I'll be a footballer in Italy!
(Boy (14) with mild mental disabilities and speech defect)

As we pointed out in Section 6, many of the children in the six 'special needs' schools and classes are very similar to some of the children in Day Centres and, to a lesser extent, in Residential Development Centres. We have recommended that the two Ministries meet to resolve, if possible, this confusion of roles. We also suggested that one longer-term strategy might be for the Ministry of Education and Local Authorities eventually to take over all developmental / educational programmes for children and view them *all* as 'education'.

As 'Education for All' gathers momentum, there will certainly be more children with disabilities requiring education. The wording of the *Normative Dispositions* (Albanian Government 2002a) possibly gives the impression that some children with disabilities might be regarded as 'not educable'. They note that, 'Pupils with severe mental or physical problems, that are impossible to treat in special schools, can be treated in other institutions depending on the individual case'. Both the UN Convention on the

Rights of the Child and the EC regard *all* children without exception to be educable that is, capable of responding developmentally to appropriate programmes.

The current reality in Albania is that programmes have only, in general, been developed for children with mild and moderate disabilities, mainly using diluted or extended versions of the national curriculum despite the encouragement to introduce more life-skills through IEPs. It is, therefore, the special schools and special classes that are not able to educate children with more severe disabilities in their current programmes, rather than these children not being educable. The previous rather general guidance, that children in Schools for the mildly retarded children should cover four Grades of work in eight or nine years of attendance, seems to have been accepted as a strict mandate. Several Special School Directors mentioned that they did not wish to include pupils with more diverse needs.

We really should not be accepting children with more severe difficulties – they do not fit our programmes. We cannot get them to the fourth Grade level even at the end of nine years.
(Special School Director)

Others were more flexible.

We can be ready for any child. Our teachers have all adapted already because they were teachers in ordinary schools before they came here, so they could adapt again, I think, if children had yet more difficulties. Training would help them.
(Special School Director)

We have already suggested, in Section 14 Recommendation 36, that all staff working with children with disabilities in all kinds of Centres, Special Schools and Special Classes undertake training that enables them to work appropriately and optimistically with children with more severe and complex disabilities. This recommendation will be further developed in Section 20.

While all the special schools had developed some form of IEPs, most did not seem to be using them to develop more individualised forms of learning. Indeed, some were using their assessments of pupils' attainments within the IEPs, to group or put pupils into classes according to these current attainments, irrespective of the pupils' ages and different paces of learning. We believe that, while age cannot be the sole consideration in grouping pupils for their education, it must be an important factor for pupils' own self-esteem (Recommendation 59). Differentiation of programmes within a class is a demanding task for teachers but without it, inclusive education will not be achievable and many children's special needs will not be met. Recommendation 103 in Chapter 20 envisages that *all* teachers should have the opportunity to develop the understanding and skills to create and implement IEPs. Despite the guidance within the *Normative Dispositions*, some Special – and mainstream – Schools did not seem to be involving parents or children themselves in developing the IEPs or reviewing them. We would like to see practice in this collaboration improving (Recommendation 60).

We discussed in the previous Section some arguments for retaining some special provision while still moving towards inclusion. We pointed out that many of the children still waiting to come into education of any kind would have more severe disabilities. We have also recommended that all mainstream schools should have a multi-purpose Resource Base in which a variety of mainstream pupils might receive some additional support or specialist teaching on a sessional basis rather than full time. We indicated that all pupils might go there from time to time to use computers, that able pupils and those with some mental or specific disabilities might undertake parts of their programmes there and that there would be a Resource Teacher in charge of the room and of the various activities (a job

specification appears in Section 20). It will be important that this room does not become stigmatised as a room for pupils with problems – it should be seen as a resource for all.

We indicated briefly in the previous Section, Recommendation 52, that there should be a special class within some 8 year schools. Our view is that some, *but not all*, 8 year basic schools should have a *small* Special Class where core teaching would be undertaken of pupils who had severe or profound mental disabilities, or complex disabilities (severe or profound mental disabilities with other disabilities such as sensory or physical impairments or autism). These classes would probably not have more than five or six children in each. Every such child, like all other pupils in 8 year schools including those who use the Resource Base from time to time, would have a peer age register class which he/she would join for some part of his/her programme as individually appropriate.

We hope that this kind of provision – the development of i) Resource Bases in *all* schools to support the learning of *all* pupils and especially those who have mild/moderate mental disabilities, and the creation of ii) Special Classes in some schools for children with more severe and complex disabilities - might eventually replace most Special Schools for children with special needs. (This does not apply to Special Schools for children with sensory disabilities, which we discuss later in this Section of the report.) We believe that a system of this kind, that is based on local eight year schools, would be a stepping stone towards inclusion, would bring more children with disabilities into education, and locate them with other neighbourhood children near their homes.

However, it is important to note that the children in the new Special Classes would be significantly more disabled than many of the children currently in Special Schools and Classes and that their teachers would require appropriate knowledge, skills and attitudes. The new small Special Class would be staffed by a Specialist Teacher (a job specification and suggestions about training programmes appear in Section 20). The creation of Special Classes, Resource Bases and the employment of their associated better trained teachers would have very significant implications for staffing and for professional development, but would require less capital investment than building more new special schools. It would also reduce costs to parents and/or Education Authorities for children's travel and make it more likely that more children with disabilities would actually attend school in more isolated areas.

Often, as countries are moving towards greater inclusion, it is suggested that special schools and their staff may act as some kind of specialist resource in the new developments. This is rarely as effective as it should be, not least because inclusive education is as new to special school staff as it is to mainstream staff. It could be argued that special school staff in Albania are originally qualified and experienced in mainstream teaching and are then, in principal, selected on the grounds of their excellence and commitment to become special school teachers. Viewed in this light there certainly should be some very good teachers who would have potential to be leaders in inclusion. However, not every teacher in special education is of this quality and, as they themselves and the Ministry of Education have pointed out, their specialist professional development has been neglected for some years. We suggest in Section 20 that special school staff and experienced teachers in mainstream schools should be given the opportunity to undertake new specialist forms of staff development in the hope that new leaders and mentors in inclusive education will emerge from them. We do not at this time, however, see them as a group leading the new developments. However, it is important that their experience and commitment is recognised and that they are encouraged to develop them further.

Special Schools for Blind Children and for Deaf Children

The two Special Schools for Children with Sensory Impairments are neighbours in Tirana but different in character and facing different challenges. Before looking at them separately we will look at some of the shared issues. We enjoyed meeting two of the senior pupils from each school and holding discussions with them. All four were admirable and able young people and excellent ambassadors for Albania as well as for their schools. One young lady with visual impairments was both skilful and confident enough to converse in English for part of the time, while one of the deaf pupils acted as occasional interpreter for his more profoundly deaf fellow pupil. We were also very pleased to meet a small number of parents from both of these schools. All spoke warmly of their schools and plainly these parents and children, at least, identified closely with the schools' aims. Where they were critical it was usually about lack of various resources for which they did not blame either the school or even the Ministry of Education but rather the national economy. The older pupils and their parents had seen how both schools had struggled to improve the children's living and learning conditions and were appreciative of this.

Such appreciation does not mean, however, that there were no problems within these two schools' systems. The schools' Directors and Deputies were conscious of problems although some of their recommendations in relation to them might differ from ours.

Both schools are residential and draw pupils from all over the country. They operate a nine-year programme, one year longer than all other basic education schools. They have some of the difficulties associated with residential schools, especially in poor countries and in countries without good transport infrastructures. Such schools are staff-intensive and expensive to run. Both schools have had NGO help in improving their material status but with the 67 blind and visually impaired pupils and the 160 deaf pupils the costs of running the school represents a major drain of finance from the Ministry of Education. Finding the right kind of educator and dormitory staff can sometimes be problematic.

At a human level, a residential school also extracts a personal toll on parents and children – that of physical and sometimes increasing emotional distance. Most of the children cannot travel independently, the schools are not funded to provide travel vouchers for public transport and some parents are poor and live at a great distance. Very many children whose families do not live in Tirana or in central Albania go home only rarely and in time they centre their lives in the schools and no longer wish to return home as often. Some parents also lose the habit of caring and visit less often. Despite this later distancing, many children feel acutely homesick when they first come to the schools and some remain homesick for a long time. In other cases, parents cannot bear the thought of parting with the child and migrate to Tirana, as no fewer than three of the five parents with whom we spoke had done. Whichever way emotions eventually resolve, residential schooling generates additional stresses in the views of most, but not all, people.

Many of our children can't go home often, and the less they go home, the less they want to go home, and the less their parents, in some cases, want them to come home. Their friends are here in the school. They can talk to their friends but the ones who have hearing parents can't talk with them. So they sometimes spend holidays here. They love them often but they've grown apart.

(Deputy Director of School for Deaf Children)

I just cried and cried – it was terrible - but my older brother was living in Tirana and he came to see me.

(Blind girl (15))

My parents moved to Tirana for our sake. We go home at the weekends.

(Blind girl (14), one of three siblings with the same visual impairment in the school)

Personally, I think it's good for them to stay at the school. It makes them independent and they gain solidarity with other blind people.

(President of the Albanian Association of Blind People)

We cannot agree completely with the last view, especially in relation to young children. The prospect of parting with young children is a key factor in some parents not sending their sensorily impaired children to school at all, and in others sending their children to school for the first time much older than the given norm of six years. However, these entirely understandable human decisions have negative effects on their children's educational development. We recommend that the Government establish agreements with parents that they must take their children home for one weekend in four as a minimum, and if possible, more often. Transport vouchers for children and for an accompanying adult should be funded by the Ministry of Education (Recommendation 61). We also recommend that both schools have an attached social worker, primarily to work on developing home-school liaison but also to work with the schools towards these children's and young people's greater societal inclusion (Recommendation 62).

An acute problem for both schools is that children arrive in the school at any time between age 6 and even up to 10, having had no early intervention or even ordinary kindergarten, and may have been both under-stimulated and over-protected. The loss of the early years for communication development in the more profoundly deaf children is a loss of personally catastrophic proportions. This is equally true of early mobility and independence training for many blind children. We reiterate this in Section 18 on early intervention and make a range of suggestions about developments in this area of work.

Before going on to discuss the two schools separately, a final shared issue was the question of post-school education, vocational training and employment.

Most of our young people are unemployed when they leave school where before they could have relied on finding at least unskilled work. It is depressing for them and us.

(Depute Director of the School for Deaf Children)

I would say that unemployment and poverty are the largest problems facing blind people today. We promote and defend higher education but there should also be other choices for young people for whom this is not attainable.

(President of the Albanian Association of Blind People)

Apart from the very able blind students who proceed to various academic secondary schools and then University, most of the school leavers from these schools experience a dearth of routes post-school in secondary and vocational education towards employment or any meaningful form of occupation, despite the best efforts of the schools. We have already recommended that this situation be addressed (Section 11, Recommendations 26 and 27).

One of the sadder findings from our interviews with the school pupils was that they all thought that the prospect of themselves, or of anyone, having a child with a severe sensory disability was sad or even frightening. They would all also, with the exception of the signing deaf girl, seek a marriage with a partner who was not disabled and who could therefore ease their way in life. This finding reflects the

reality of Albanian life currently, that there are many very substantial problems in day to day life for people with sensory disabilities. In societies that are better developed for people with sensory disabilities and where 'disability pride' is widespread, it would be unusual for young people to hold such negative views of their own condition.

Having a deaf child – oh no – that would be terrible. I would not want that at all. I would bring her here to the preparatory class. I'd have a deaf husband and he would understand me.
(Deaf girl (16) through an interpreter)

School for Blind Children.

The school is a nine-year school for children age 6-18. It follows the mainstream schools' eight-year curriculum. The Director believes they succeed well in this curricular aim for children but with considerable effort by staff. The school, or education for blind children (currently they are synonymous as there are no other educational facilities for children with visual disabilities) faces several problems.

The first relates to the school population. The Director believes that the school's recruitment process, managed by the school and the Ministry of Education, is under-recruiting, *'Currently we recruit about seven children each year – I believe it could be nearer 20'*. With a roll of 67 children currently, the school is not full. It is certainly likely that there are other eligible children and improved links between the schools and Local Authorities (see Section 15, Recommendation 46) should help identify them, as would any Census or counting project (Section 7, Recommendations 17 and 18). However, there are only a small number of pupils with mild mental disabilities and visual impairments in the School and the Director believes that, even with IEPs, these pupils should be taught in separate classes. This view was echoed by one pupil, *'I don't think the school should have children with additional learning difficulties – they hold the class up'*. This statement suggests that teachers do teach in 'whole class' ways. Overall, we do not agree with the view that children with mild/moderate mental disabilities should be excluded from the school or taught separately. We do acknowledge that it is difficult to differentiate teaching. We think that all staff, sighted and blind (the school employs five blind teachers), would benefit from staff development in this respect (Recommendation 63).

We also think that there may be some pupils currently who have visual impairments who might not necessarily need to attend the School for Blind Children if they were equipped with better low vision aids such as good quality magnifiers, close-circuit TV equipment and lap-top computers. Only one of the present Grade 8 pupils actually uses non-sighted methods (Braille etc.) although all can read and write using Braille. We do recognise that any child who is at risk of becoming blind as a condition deteriorates must become competent in non-sighted methods, but children who have probably non-deteriorating conditions could use low vision aids within a mainstream school. The cost of importing these aids is certainly less than the costs, financial and personal, of having these children in residential school. We would recommend that a national approach to the provision of appropriate detailed optical testing and free supply of spectacles and other low vision aids to children be prioritised after the present broad national screening. This is likely to bridge both the Ministries of Education and of Health (Recommendation 64).

Any possible relocation of pupils with visual impairments to mainstream schools, even with good low vision aids and peripatetic support, would be a highly contentious issue for the Albanian Association of Blind People. Such a move might mean that the school would then find it harder to identify a viable cohort of very able blind pupils, threatening to some extent the School's continued existence and certainly its record as an elite academic establishment. The difficulty in maintaining such a role is exacerbated as, with better infant and maternal care, the numbers of intellectually able blind children

has reduced (care of premature neonates has improved). We recommend that, as blind children are identified, the nature of each child's condition should be recorded, particularly in terms of the likelihood or otherwise of retaining educationally useful vision, and that this should be taken into consideration when recommending educational placement (Recommendation 65). The Government should also take advice and obtain supplies of low vision aids to support inclusion of children with non-deteriorating visual impairments who have usable vision and who could be placed in mainstream schools (Recommendation 66).

On the other hand, the proportion of blind children with *additional* disabilities, particularly with severe mental disabilities, has increased within the general population world-wide, but the School Director and AABP do not think that this School would be the correct placement for them. (Internationally, most Special Schools for Blind Children *do* make provision of a semi-detached kind, for children with dual or complex disabilities.) The school in Tirana has no visually impaired pupils with severe learning difficulties, nor did we identify any blind children with learning disabilities in any in the Special Schools for children with special needs or Day Centres that we visited. We did meet one blind child with very complex additional disabilities at home with his family and heard of three others and have no doubt that any census or counting project would identify many others. We believe that, in the longer-term, these children when identified should *not* attend the residential School for Blind Children but should, rather, attend a local Special Class. Support for the child, Specialist Support Teacher, Educators and parents, would be provided by a Peripatetic Specialist Teacher (Visual Impairment) based in the School for Blind Children (Recommendation 67) and by a specialist Mobility Teacher who would work both in and out of the School for Blind Children. The level of mobility of the blind pupils is poor and the School currently has no trained mobility teacher.

I don't go about on my own – the traffic is terrible and we are not allowed to, although I will when I go to High School. I think I could get to someplace if I had an address but I would be frightened. When I go to High School, we will solve the problem in the family, perhaps my cousin will come with me.

(Able girl (14) with visual impairment)

We have recommended in Section 20 Recommendation 107, that an existing teacher or educator within the School be trained as a qualified Mobility Teacher.

While the blind teachers did themselves require some additional practical support, pupils appreciated them.

They probably do understand us better but then of course they can't teach you practical things so we need sighted and blind teachers.

(Girl (15) with visual impairment)

The school holds a very special place in the hearts and minds of Albania's community of blind and visually impaired people and is, in particular, supported strongly in an emotional way by the Albanian Association for Blind People as part of their collective identity. AABP is a powerful lobbying body, in common with other similar bodies in other countries, mainly thanks to its elite leadership of vocal well-educated professional members. It has, uniquely among disabled groups, the right to decide the various levels of visual impairment for Social Benefits systems. There are special protective legal and financial measures for blind students in University. Asked if some of the measures and the special status of the school accorded to it by AABP were not rather elitist and exclusive, the President of the Association insisted that it was assertive and very realistic in the face of Albania's current socio-economic situation.

One issue highlighted in our meeting with the representatives of AABP and by the Director of the School was the difficulty in obtaining sufficient Braille texts for blind people – adults and children. AABP hopes to establish a Braille Press. This matter was raised both by pupils and parents. Parents also raised the matter of children who were musically talented needing musical instruments at home – an item well beyond the budget of many parents. The pupils were more philosophical about this shortage of resources than the parents we met but the absence of low vision aids and of microtechnology is a loss of very serious magnitude to these young people.

In richer countries computer technology software development for blind people has revolutionised communication for them with the use of print-to-Braille scanners and voice-to-Braille or print synthesisers. These allow blind people to participate in the written world of the sighted community and open up new fields of study and employment to them. These developments should not supplant the teaching of Braille and the use of Braille and other non-sighted communication aids as it will be some time before such electronic equipment and software is widely available and yet more years before it is available for individuals' private use at home. Currently, therefore, the still young blind children and young people need to acquire good Braille skills before progressing to electronic technology. Children with stable conditions of visual impairment who can use sighted methods should be equipped with low vision aids. We recommend that a Donor be sought to fund a member of the school staff to train in the use of specialist software and to fund the purchase of relevant hardware and software for the school (recommendation 69).

I was at a mainstream school and so were my brothers and we did well there before we came here to the School for Blind Children. I can't say one or other school was best. Maybe I would have done well enough in any school. However, our father thought our vision might deteriorate and he was worried because there was no-one in the local school to give us specialist advice. I can use Braille but I don't need it. What I do need is extra time to read slowly and carefully and I get that from all our teachers here in our small classes. I don't think we have all the equipment that would help us, probably it is too expensive for Albania. But we help each other and the educators help us in the afternoon too.

(Girl (14) with visual disability)

The description given by the girl, above, paints a recognisable picture of the school currently with its strengths and its areas requiring development. We recommend that a future scenario is discussed in which the School for Blind Children would be not only a school but also a resource base for outreach services to blind and visually impaired children in other locations such as children with severe multiple disabilities in Special Classes, children with milder visual disabilities in mainstream school classes and Support Bases, using low vision aids, and pre-school children wherever they are placed. The school itself might have a non-residential pre-school facility, residential facilities as now for 6/7-18 year olds and teaching for 3-10 year olds. The upper cycle of the school for 10-14 year olds might be linked closely to a nearby mainstream school so that pupils from *both* schools could benefit from greater inclusion (Recommendation 70).

School for Deaf Children

The school is the only school for deaf children in Albania and is full with 160 children. There were reports of a small NGO centre in Lezha but the research team was unable to confirm its continued existence or to visit it. Previously the Special School had around 200 pupils but this resulted in an unmanageable situation. Numbers were reduced by the removal of 'misplaced' pupils - children who were aphasic but hearing, elective mutes, and deaf children with additional disabilities. The school is selective in that it accepts only the most severely deaf children of normal or near normal intelligence. There is a small number of children with some degree of mental disability but this is not officially acknowledged. This year 50% of applicants were turned down. There are other parents who do not wish their eligible children to attend the school, sometimes because it would mean distant children becoming residential as we discussed at the beginning of this Section, and sometimes because parents have not yet fully accepted their child's deafness and the need for different educational strategies.

This immediately raises the issue of what happens to these children who are not accepted or who are profoundly deaf but whose parents do not seek their admission. No records are kept by the school of 'rejected' applicants although the Depute Director hoped that other Special Schools for children with special needs might accept them. She was also in touch informally with a number of families whose children had been refused a place, offering them advice. We have already made recommendations about recording the details of children who are identified as disabled or are refused special school or other school placements (Section 7, Recommendations 17 and 18). The Albanian National Association for the Deaf (ANAD) estimates that there are around 3,000 deaf people in Albania. Statistically, this suggests that about 1,000 of these people will be children in the 0-16/18 age group. This in turn suggests that there are very substantial numbers of deaf children in Education or occupation of any kind and who are, therefore, at home. No indication was given of the causes of deafness although there appeared to be quite a high level associated with meningitis, encephalitis and various ear conditions such as mastoiditis and chronic middle and inner ear infections. Within the Special School about 20-30 children currently are from 'deaf families' (families with one or more deaf parents and where deafness is a genetically inherited condition). These families are important for another reason to which we will refer later in this section.

Given the that the School is already full and that there are large numbers of children, some of them profoundly deaf and some with additional disabilities, we consider that we do exceptionally have to recommend that another special school should be opened. We believe that it should be in Shkodra or Vlora in order to offer more geographic proximity for children and families. We do not underestimate the costs or the professional difficulties in undertaking this development and suggest that this is a major project in which Government, international and local NGOs and Associations should be involved. It would be a project that would also be suitable for a wealthy donor (Recommendation 71).

We also suggest that both the existing Special School and the new Special School should include children with mild to moderate mental disabilities as well as the current population of more able pupils and that there should be more differentiation and use of IEPs (Recommendation 72). We think that both Special Schools for Deaf children should develop day kindergarten facilities, and outreach support teams for children with lesser hearing difficulties in mainstream schools and kindergartens or other Special Schools (for children with special needs) and Special Classes (Recommendation 73). We believe that children with more severe and complex disabilities, including deafness, should be placed locally in day Special Classes attached to mainstream schools with peripatetic support offered to Specialist Resource Teachers and other staff by specialist teachers (Specialist Resource Teachers (Deaf Education)) from one of the Special Schools (Recommendation 74). A missing but vital role in the school is that of audiologist. The pupils in the Special School were assessed for hearing aids by an Italian NGO's audiologist. We have recommended in Section 20 Recommendation 107, that an

audiologist be trained abroad and that he/she should work across both the existing and new Special Schools for Deaf Children.

The Current Special School teaches an extended form of the basic curriculum and tries to achieve four Grades within the nine years of possible attendance. The school adds communication/speech and Albanian is obviously taught with different approaches. There is no secondary school for deaf children and the hope of any deaf young person going on to University is currently extremely remote. While academic attainment is always harder to achieve with severely deaf, basically non-oral/aural communicating pupils, this level of attainment is low. This is especially so when the actual cognitive ability of the current pupils is estimated to be at least average and probably includes some very able pupils. The nub of the problem is the poor communication between teachers and pupils, a problem of long standing and one that is widely contentious not only in Albania.

The problem can be illuminated by an analogy. A class of Albanian people is asked to develop new knowledge and skills in, for example, geology, which none of them has studied before although they are all people of good general intelligence. They will be taught by an African professor of geology, who has been learning Albanian on his own for a few months by trying to read a few Albanian novels borrowed from his Albanian neighbour who left the country thirty years ago. The African professor will teach his Albanian students using his rudimentary knowledge of Albanian, augmented by his own language, Swahili, and a few geological diagrams. There will be no interpreter and there is no dictionary. There is one Albanian in the class who has lived in Africa and remembers a few words in a different dialect of Swahili. Nor surprisingly the class progresses very slowly, some students drop out and most others have serious gaps and misunderstanding in their knowledge. However, the African professor is making some progress in understanding Albanian

The official mode of communication at the School for Deaf Children is one that combines finger spelling with some gesture and, on the part of staff and a minority of children, some oral Albanian and the use of lip-reading. The overall result, as the long-serving Depute Director agrees, is a slow and laborious form of communication, sadly inadequate for the tasks of teaching and learning. In the circumstances it reflects well on the mutual efforts of staff and pupils that they achieve as much as they do.

The children in the school, meantime, use the school's form of Albanian Sign Language for personal communication among themselves. The School staff's view is that there is no Albanian Sign Language (ASL). In fact, any country's 'official' sign language is actually an *evolved* signed language with its own grammar, styles of language etc, and often with local 'dialects' and even family variants. ASL is less developed and coherent than many national Sign Languages because deaf people have not had the opportunities to come together to the same extent and because its only special school has not fostered the development and use of ASL.

While communication – signing, oralism, sign-accompanied Albanian (total communication), Albanian Sign Language, finger spelling – has always been a highly contentious topic, there does now seem to be an emerging view on communication and deaf people that is gaining international consensus. Current thinking indicates that simultaneous use of speech and its supposed sign equivalents (sign-accompanied Albanian or total communication) actually tends to reduce, impoverish and slow down both the signing and the speech and to slow the whole communication and understanding processes substantially. The same also applies, even more so, to finger-spelling. *A bilingual approach, Albanian Sign Language and Albanian, to communication appears to be the answer.*

For most or all of the School's severely deaf pupils – the great majority are severely deaf – sign will be their first language, even if their parents are hearing. It will be their natural urge. To deprive them of it

is a great mistake as we now know from research into bilingualism. This shows that it is the strength of the first language that helps develop the second, if a second language is required. Thus good signing would give a child who wishes or is required to learn Albanian as a second language an *advantage*, not a disadvantage. Signing competency increases the capacity to learn and understand Albanian. The *oral* use of Albanian can be fostered in bilingual children by appropriate speech development but only a minority of students will become really intelligible. Sign will be the easiest mode of learning. It may even be the *only* way of learning about more complex and abstract matters, some of which, for instance, underpin social and moral behaviour.

It is very difficult to help our deaf pupils to understand about relationships and appropriate social behaviours and about anything that is not directly obvious. We do not have the communication to deal with abstractions.
(Depute Director of the Special School for Deaf Children)

I like all the staff, teachers and educators and the dormitory staff, but especially we all like one educator who signs very well.
(Deaf girl (16) on being asked about her relationships with staff by interpreter)

I would like all young people to learn to sign and I wish I could sign like one girl in our school. She is really good and everyone goes to her for help with the lessons.
(Deaf boy (16) who can hear a little and speaks intelligibly)

The school has tried to help hearing parents of deaf children acquire rudimentary communication skills, recognising how important this will be to family relationships, but they have only been able to teach their own strategies.

We have learned some signs and finger spelling from the school so we can communicate slowly and very simply together.
(Mother of deaf boy (10) who appreciates the help but also understands that it is not enough)

We do not think that the issue of signing can or should be avoided. It is an issue of the greatest significance to deaf children now and in their future adult lives. We believe that the teachers at the school should be required to improve their signing. Better signers within the school's staff and senior pupils should be asked to support other staff and pupils, *including within the classroom*. The school must also involve the members of the deaf community including their more able former students to be assistants in this development, in particular to help deaf children of hearing parents, and the parents themselves, to learn to sign and help family communication. It is unfortunate that opposing positions seem to have been adopted by some staff associated with the school and with the Albanian National Association of the Deaf (ANAD).

ANAD began in 1993 and in 1996 became a member of the World Federation for Deaf People. It is supported financially by a Finnish organization and has 133 deaf members. Its objectives are:

- ❖ to improve the educational system for deaf people
- ❖ to create and unify the sign language
- ❖ to recognize sign language as a minority language
- ❖ to extend the use of sign language and work for the integration of deaf people

ANAD would like the Special School to work with their Association in the introduction of sign language into the school but they have been unable to achieve this aim. Several former pupils of the Special School are now involved with ANAD.

Generally the teachers in the special school are good but the use of sign language would help pupils achieve more than four grades in eight years of schooling. I would also like pupils to have more activities beyond the school itself and more contacts with people outside the school. I think ANAD could support the school in learning sign language. If I had a deaf child, I would put him in the school for deaf children, but on condition that he learned sign language so that he would learn more than I have learned in school.

(A former pupil of the Special School for Deaf Children, now involved with ANAD)

We recommend strongly that the Special School and ANAD along with their respective supportive Italian and Finnish NGO representatives are brought together to find a way forward in introducing Signing and developing ASL. Given the issue's contentious history we would also suggest that this process be undertaken with the support of a knowledgeable mediator, nominated by the Ministry of Education to ensure that acrimony is minimised and constructive ways ahead found (Recommendation 75).

There is a strong feeling within ANAD that, as in some other countries, ASL should be developed, supported and given official status as a minority language and that hearing children could chose to learn it as a foreign language. We are sympathetic to these aspirations but feel they lie some way in the future and that we should prioritise other issues. ANAD was very conscious of the lack of trained interpreters in ASL-Albanian and thought that ANAD could be instrumental in their training. There is also a need for Social Workers to work with deaf adults and children. Key to developments in both these professions are *hearing* children born into families where one or both parents are deaf and where deafness is a genetic factor. These children are truly bilingual and in many countries form the core of the professions of Signing interpreters and of social workers for deaf people. We recommend that the Government and ANAD work together to identify potential Signing interpreters and social workers and to advance their education and training (Recommendation 76).

Television has enormous potential as a source of information, entertainment and further education for deaf viewers, both adults and children. It can also be used as an educational resource in the development and propagation of Albanian Sign Language and Albanian language by the use of Sign interpreters and by unambiguous succinct Albanian subtitles. We recommend that all Albanian TV stations be required as part of their licensing agreement to take account of deaf viewers and to provide increasing hours of interpreted and sub-titled programmes (Recommendation 77).

The school is very conscious of the lost educational opportunities caused by late diagnosis, poor and late supply of hearing aids (despite the generous help of an Italian NGO in this respect), and the lack of pre-school education, all vitally important in the cognitive and language development of deaf children. We have already recommended that the Special School or Special Schools both develop day kindergarten provision and a peripatetic support service to undertake outreach work in other educational provision. We would further recommend that a national approach to the provision of appropriate detailed audiological testing and free supply of hearing aids to children be prioritised after the present broad national screening. Such a system would need to bridge both the Ministries of Health and of Education (Recommendation 78).

New Special Education Units for Children with Autism and for Children with Specific Language Disabilities.

We remarked that several Special Schools, Day and Residential Developmental Centres and both Ministry of Health children's Centres had children on the Autistic Spectrum, usually with Kanner Syndrome in which autistic features are combined with some degree of mental disability. Although none of our interviewees specifically mentioned children with Asperger's Syndrome, in which autistic features are combined with at least average abilities and sometimes with very high cognitive abilities and other talents, they do exist in Albania as in all other countries. As in other countries, again, we believe that numbers of autistic children are probably increasing, not just because of better diagnosis but also because there appears now to be a higher incidence of autism although the causes are not known. The Ministry of Health Centres in Tirana largely function as diagnostic and therapeutic Centres and provide educational activities largely because appropriate education is not available elsewhere. This appears to be a significant gap in the Ministry of Education's special provision. We recommend that a new Special Education Daily Unit for autistic children be established at the Special School for children with special needs in Tirana (Recommendation 79).

The Unit would have multiple purposes. It would educate children who lived within daily travelling distance of Tirana and who had been diagnosed as autistic at either of the Ministry of Health Centres. It would aim, where possible, to facilitate children's inclusion either in the main part of the special school or, preferably, in their own local school, either included with support in the mainstream or in a Special Class. In order to help this process of transfer from the small Special Unit to either the larger Special School or the local school, the Unit would also act as a training unit for the teachers from the school that would be receiving these pupils.

Where it was considered that the small special unit was the optimal environment for any child (some autistic children, but not all, find larger and less predictable environments unbearably frightening and confusing) the Unit would continue to act as a longer-term source of education. The Unit would require a minimum of two and probably three teachers, especially if an additional role of outreach advisory work to other schools and Centres was to be possible, and four educators. The Unit would require four rooms and should not accept more than 12 to 14 children at any time. Plainly this would be a resource intensive project in which the Ministry of Education would require substantial NGO and donor support, especially as international staff development would be desirable before the Unit was opened and at intervals thereafter.

We were also concerned that there appears to be no specialist educational provision for children with more severe specific language disabilities such as aphasia, severe dysphasia or, debatably, elective mutes. Neither is there any service for children who are effectively either mute or unintelligible because of cerebral palsy and who require augmentative or alternative forms of communication. We know that some children with specific language disabilities were previously enrolled in the Special School for Deaf Children but were removed from there some years ago. Some children with such disabilities may be in Special Schools or Centres but it seems unlikely that they are receiving the kind of intensive support that they need. We discuss the situation in relation to levels of training of speech and language therapists in Section 20 and recommend there that two students be seconded for international training in speech and language therapy – a probable four-year period of time. We do not feel it would be appropriate to start a Special Unit for children with severe language disabilities before the right kind of specialists are available. We would therefore only recommend at this time that a second Special

Education Unit should be established in the same location but with its own accommodation, resources and staff, as and when two fully trained speech and language therapists become available (Recommendation 80). At that time two Resource Teachers, or Specialist Resource Teachers would also be allocated to work with the therapists and the Unit would accept up to 12 pupils, again with the aim of facilitating their inclusion in their home schools where possible.

Section 18: Educational early intervention

There is no government-provided pre-school educational provision specifically for children with disabilities, although the National Centre for Development and Rehabilitation in Tirana does have therapeutic and developmental activities for children who attend the medical clinics there, including many with cerebral palsy, autism and other conditions. ADRF –Nano (2002) records that there have been earlier attempts during 1994-6 to integrate some children with mental disabilities in Tirana Kindergartens, and more recently in 2001-2 the Institute for Pedagogical Studies, funded by the Soros Foundation, also successfully integrated some pre-school children. As with all too many successful pilot programmes, these stopped when funding ceased.

We suggest that early intervention should be seen as a sustained high priority by Government and by NGOs for children with disabilities and especially for those with all kinds of disability at the more severe end of the spectrum (Recommendation 81). We have also recommended in the previous Section of the report that the Special Schools for Blind and for Deaf Children make some specialist pre-school provision on a day basis rather than residential. The early years are vital for the development of blind children's sense of curiosity and their mobility, for the development of oral and/or sign language and comprehension in deaf children, for the maintenance of health and optimal movement in children with physical impairments, and for the cognitive development of children with mental disabilities.

While a loving and supportive family is the most important factor in the life of any child, early positively developmental activities lay the foundation for subsequent learning. This early learning usually happens naturally within a family that is caring of and attentive to their children who do not have special needs or within the kindergarten for the minority of children who attend them. *However, it cannot be assumed that this will be so when a child does have special needs.*

A child with special needs may seem less responsive and therefore be less 'rewarding' to parents and others who try to stimulate him/her, so the parent may stop trying and come to believe that the child is not capable of response or of development. Children with impairments may need particular forms of structured stimulation that are not necessary for other children and most parents will not be aware of these needs or of appropriate responses to them. They may even come to believe that they are failing as parents, first, because they have produced such a child, and second, because the child seems unresponsive to them.

It is important that health, social services, education services and relevant NGOs and Associations work together to ensure that children with special needs, once identified, are offered support and positive interventions as early as possible. It is important that parents are supported and encouraged to love and stimulate their child and are given hope for their child's development (Recommendation 82). Early medical contacts can contribute much to this although sadly, some of the parents with whom we spoke remembered more negativity when desperately seeking support than constructive advice.

He just said 'Take her home and don't hope for much from her, she may not even live.'
(Mother of girl with Down's Syndrome)

Advice, through visiting personnel, leaflets, and the media, should be available to families from the time they are first made aware of their child's condition, if possible shortly after birth. Much could be achieved through the production and transmission of simple friendly films on public education TV channels, demonstrating parents playing and working with their children with special needs (Recommendation 83). We recommend also that the National Centre, the Department of Mental Health, ADRF's Advocacy Group and other NGOs and Disability-related Associations collaborate to develop a *range* of early intervention programmes, sharing expertise and training to try to cover the

range of early intervention needs across the country. Programmes should link with existing public and private kindergartens, and with existing community-based inclusion and home-visiting programmes for older children. In some cases of missing Albanian expertise, it may be necessary to bring in qualified international professionals (Recommendation 84). In Section 9, Recommendation 22, we emphasised the extreme importance of involving mothers in working with their children. In early intervention it is vitally important to encourage and empower parents and never to usurp their most important role while supporting and advising them (Recommendation 85).

Findings from reliable research studies demonstrate the importance of early intervention with children with disabilities (and other children), reinforce some of the points already made in this Section and that also offer constructive ways ahead:

- ❖ Early deprivation has lasting and increasingly negative impact on later educational and social attainments.
- ❖ The earlier and more sustained the positive developmental intervention is, the more effective it is.
- ❖ Involvement of mothers or mother-substitutes and of home support for the programmes of intervention is linked to more lasting and positive outcomes.
- ❖ Small class sizes and high teacher-to-child ratios (not simply adult-to-child ratios) are also correlated positively with optimal learning in the early years.
- ❖ Those children that gain most from early intervention are those who are potentially at greatest risk of developmental neglect (including children with disabilities and those at socio-culturo-economic disadvantage).

Section 19: Health services

No member of our research team has medical qualifications although the international consultant regularly works and researches in the interface areas of health services and education. However, we are more tentative in our recommendations in this area and hope that matters raised within this Section may be taken forward for discussion by the relevant paediatric sections of the Ministry of Health. We discuss in this section the work of doctors working in a range of services and at various levels, dentistry, and refer briefly to what are now termed in the UK 'Professionals Allied to Medicine' (PAMs) including various different branches of therapies.

We have already highlighted in Section 6, Recommendation 15, a possible need for clarification between the roles of the National Centre for the Development and Well-being of Children and the Department of Mental Health and the need to facilitate collaboration between the two Ministry of Health Centres. We have also already noted in Section 17 the need for national screening for children with sensory impairments and their subsequent more detailed assessment for low vision aids and spectacles and hearing aids and the free provision of these. We anticipate that this would require collaboration between the Ministries of Health and of Education. We discussed in Section 4 the centralisation of many specialist services, including medicine, in Tirana and how this may impact negatively on the lives of children with disabilities and their families.

The general picture of medical care is one of a service under pressure. Both general practitioner and specialist doctors' conditions of work were often far short of ideal and the contexts of financial and material poverty in which their patients live, sometimes allied to adherence to old childcare practices in families, meant that doctors clearly had to adopt an educational role as well as a medical one. Understandably, they sometimes achieved less than they might have done in better circumstances. That they continue to struggle for their patients says much for their professionalism and dedication.

This is what we have – one specialist for the whole country and - as for physiotherapy, well, we do what we can with the personnel we have and with parents. We can supply children with cost-reduced enzyme supplements but not the best kind and parents must pay for the antibiotics themselves. Some children need antibiotics constantly. My oldest patient is 17.

(Medical specialist in Cystic Fibrosis – a life-shortening condition that includes poor absorption of nutrients and congested lungs. Many patients with CF live until their mid or late 20s or even early 30s in other European countries.)

Medical care is likely to feature in discussions about children with disabilities in relation both to access to care that is incidental to disabilities and to disability-specific medical care. Children with mental disabilities may, for instance, have other non-related medical conditions of a longer term or transient nature for which they may need medical care of either a general or specialist nature. This can raise questions about how far these services are delivered with sensitivity and insight and also with equity. Do general and specialist medical services that are not directly related to disability have the necessary knowledge, skills and attitudes to meet the entitlement set out in Article 24.1 of the UN Convention on the Rights of the Child (UNICEF 1989)? We certainly had the impression that the great majority of medical and medically related professionals were striving to achieve this. Parental comments in relation to general local medical care were very variable but overall positive.

My doctor at the local clinic is wonderful. She cares about me and my son, I think. She tries to maintain his health although he is very frail but she does not give up hope.

(Mother of boy with physical and mental disabilities)

We only go to the doctor if we have to. I don't think he feels our daughter is worth the effort, that she is somehow not a real human being. But he does treat her.

(Mother of daughter with severe mental disabilities)

We were concerned, however, that two Residential Developmental Centres spoke about not having proper regular local medical services for their residents. The precise circumstances were not made entirely clear to us in these cases but we recommend strongly that the Ministry of Health and medical training in Universities should emphasise the equal right to medical care of people with disabilities, including those in institutional care (Recommendation 86).

Medical personnel are perceived by parents as important in supporting their own understanding of their child's disability. We thought the practices in the National Centre for Development and Rehabilitation of involving parents in learning groups and in passing them relevant published material about their child's condition were very valuable. One special school had received some in-service training about Autism from an interested doctor. We appreciate that 'educational' contacts with teachers and parents take precious time from more direct medical practice but we still see it as time well spent.

However, some practices seemed less than ideal, especially as reported by parents. We referred in the previous Section of the report to parents' accounts of being first told about their child's disability with apparent insensitivity. It may be that there is no 'good' way of delivering such difficult information but there are certainly some ways that are less bad than others. Offering encouragement, referring parents to support organisations and assuring them of some further contact are the kind of steps that good practice requires. It suggests that greater emphasis may need to be put in medical training on both interpersonal skills and on disability awareness (see Section 20). Some parents also spoke of the difficulty in accessing specialist medical attention when their child was first perceived as having special needs of some kind, of getting a diagnosis of any kind, and in getting constructive advice about how they might help their own child. Many parents reported having no on-going specialist medical surveillance of any kind and no contacts with the original doctor or hospital where they had first had their child's disability confirmed.

Medical specialist? We went to Tirana once and he told us what kind of fits our son was having but we haven't been asked back and the doctor here says no specialist in Albania could help our son.

(Father of boy (5) who is blind and has epileptic seizures)

However, one Ministry of Health Centre does offer parents a 'named contact' that they may call for advice and it was evident in the Paediatric Department of the Mother Tereza Hospital in Tirana that several specialists had close and supportive contacts with families. We recommend that, wherever possible, parents of children with disabilities be given a medical 'contact person' from whom they could seek a follow-on consultation or advice (Recommendation 87).

In a few cases parents were aware, or thought, that special treatment might be available abroad that was not available in Tirana. In some cases they had pursued this at great personal financial cost and with mixed results.

She had two operations for her eyes in Italy – one was successful and the other was not. This was a difficult time for us.

(Father of girl with severe visual disability)

He could have an operation to help his spine if we had the money to pay, but we don't and so we watch him getting worse.

(Mother of boy with physical and mental disabilities)

The pursuit of a 'cure' is a normal parental response to a child's disability, particularly in the early years, and this response is exacerbated in Albania when the country's economic situation of necessity limits medical responses. The reality is that some conditions might be better treated, if not cured, in other countries or sometimes in Albania itself but at a significant financial cost to parents. Some less educated and assertive parents who might still try to find the money for such treatment do not have the 'connections' or know-how of how to find out what possibilities exist. All of this is deeply distressing to families and frustrating and depressing to Albanian doctors.

We have already been critical in Section 12 of the medical procedures and criteria involved in claiming social benefits payments and suggested that a radical review was necessary. It was also apparent that there was a shortage of paediatricians and of general practitioners that were well informed about, and qualified in, disabilities, especially outside Tirana. We recommend that the Ministry of Health try to alleviate the present situation with more training posts (Recommendation 88).

The various levels of payment for different medicines were complex even for medical practitioners and pharmacies to grasp and beyond the understanding of most parents. They were also inequitable with parents of children who required medication that was 'full cost' having to pay the price, even if their child might require this medication for his/her entire life. We would like to recommend that, ideally, all medication that is required for long-term conditions should be free. Failing this, we recommend that costs must be substantially reduced. In some smaller specialisms, such as oncology and cystic fibrosis, financial or best quality medication donations would make very substantial changes in quality of remaining life (Recommendation 89).

Some parents implied that doctors charged for verification of children's disabilities for the KMCAP process and for medicines when such payment was not legally required. We have no means of verifying or of discounting such views. However, we do think that both medical practitioners and their patients' families should be clear about what payments are, or are not, due and what the costs should be. We suggest that the Ministry of Health could prepare succinct and easily understood guidance that could be displayed in clinics, hospitals and pharmacies (Recommendation 90).

Currently it seems that some psychiatrists and/or neurologists undertake assessments of children whose mental abilities are being assessed prior to final acceptance for Special Schools (for children with Special Needs). We have already discussed equity issues in relation to assessment of children's abilities in Section 3 of the Report. We believe that developmental or educational psychologists should undertake such assessments when possible rather than psychiatrists or neurologists (Recommendation 91). We were also concerned at some reports that suggested that doctors were advising parents either about whether a child was 'educable' or not. We do, however, understand that a doctor of a fragile child with a serious disability or a serious medical condition might make a judgement about a child's physical fitness to travel to or attend school but do not accept the concept of a child being 'ineducable'. No person involved in the assessment of a child should describe the child as, or recommend that a child is, 'ineducable' (Recommendation 92).

A small but still significant number of children with disabilities and with medical conditions have life shortening or life threatening conditions. They include children with mucopolysaccharide conditions, Friedrich's Ataxia, Duchenne Muscular Dystrophy, Cystic Fibrosis and some childhood cancers. This list is not exhaustive. Both they and their parents deserve optimum support. There is no children's hospice in Albania, nor are there plans for one, although currently an adult hospice is being developed.

We do not support the idea of a hospice for children at this time, believing that most families would wish to look after their own child at home wherever possible. In the future we would like to see a domiciliary paediatric nursing service developed to help families with the care of their dying children, and we would also like to see a suite of rooms for children and their families being attached to the Paediatric Department of the main hospital in Tirana when home care is not possible in the final stages of their medical condition (Recommendation 93). The latter would be an appropriate donation.

In the next Section of the Report we discuss professional roles and training, including some rather brief reference to some of the Professions Allied to Medicine (PAMs) (physiotherapists, speech therapists and prostheticists) who have a significant role in relation to children with disabilities. Occupational Therapists who specialise in advising patients/clients with disabilities about facilitating their daily lives and about the availability of aids to help them, do not seem to exist as a profession in Albania. Overall, our impression was of a shortage of such professionals and, in particular, a shortage of those with full qualifications and extensive experience. The role of Swiss Caritas in the training of, for example, four physiotherapists in the National Centre for Development and Well-being of Children and seven prostheticists in the Military hospital has been immensely valuable in providing a core service in these areas.

We were concerned that children in hospital for longer-term treatment in the Mother Tereza Hospital Paediatric Department and in the Military Hospital Orthopaedic Department received little or no education in hospital, were liable to become 'socially dislocated' from their peers and friends at home and that their psychological welfare was considered to be at some risk by the medical specialists involved with them. We recommend that the Ministry of Education provides appropriate educational and psychological services in consultation with both hospitals, based in the Mother Tereza Hospital but serving both establishments (Recommendation 94).

Finally, we would like to draw attention to the area of dentistry in relation to children with disabilities. A significant number of parents across the country spoke of the extreme difficulty that they had in getting their children's teeth treated.

They take one look at his teeth and decide that they could not possibly do anything with him and yet he frequently cries for days on end because his teeth are so bad. I don't think it is because they don't think he is worth it. I think they are frightened about how he would react and also his mouth is so deformed that they have no experience in that kind of work.

(Mother of boy (10) with physical and mental disabilities)

One dentist said he would do it at double the usual cost and I would have to agree to have her anaesthetised at my own expense so that he could do it all in one session.

(Mother of girl with mental disabilities and autistic behaviours)

Our son has never had dental treatment. We have asked three dentists in our area and they have all refused.

(Father of boy (10) with athetoid cerebral palsy)

We recommend that an NGO and/or Donor support the Ministry of Health and children with disabilities by:

- ❖ equipping a mobile dental unit with disabled access,
- ❖ paying for post-graduate specialist training abroad for a qualified and interested dentist,

- ❖ funding the employment of a dentist, trained dental nurse and anaesthetist, and
- ❖ covering the running costs of the Unit to undertake peripatetic dentistry across Albania for children with disabilities who have not been able to access other dental services. (Recommendation 95).

Section 20: Professional roles and training

A number of professionals are involved to a very significant degree with children with disabilities even if these children are not the only group of people with whom the professionals work. They include:

- ❖ Teachers and educators
- ❖ Residential and practical auxiliary workers
- ❖ Social workers
- ❖ Psychologists
- ❖ Doctors (a wide range from general practitioners to senior specialists)
- ❖ Dentists (general practitioners and orthodontists)
- ❖ Professions Allied to Medicine (Physiotherapists, Speech and Language Therapists, Nurses, Psychotherapists, Prostheticists)
- ❖ NGO organisers and workers

One of the largest challenges facing Albania is that of professional training/education. Some professions are fully professionally trained to at least graduate level with a minority elite proceeding to post-graduate study either in Albania or abroad. These professions include medicine and dentistry. Both psychologists and social workers now have four year graduate qualifications from Tirana University although the picture was clouded by one year trained social workers (completing courses between the years 1993 and 1996) and, in some situations, untrained graduates in social worker positions. Some roles that might be seen as those of educational or developmental psychologists such as assessment of children's abilities, are still carried out sometimes by psychiatrists and neurologists. We suggested in the last Section of the report that this should be more clearly a role for psychologists as more enter the field of education.

Other professions, such as those with an educational remit, may have several levels of qualification from pedagogical secondary school (for educators) to pedagogical universities such as at Elbasan (for teachers of the lower cycle of eight year schools) and Tirana University (for teachers of the upper cycle and secondary schools). We found that residential and auxiliary workers had a great diversity of qualifications and sometimes no professional qualifications at all and very varied levels of education. NGO workers tended to be highly educated but again with very diverse professional qualifications or, more rarely, none. Yet other professions are really only partly professionally developed and function, in general, in a very basic and sometimes outdated way unless they have had additional intensive training through international NGOs. The professions most obviously in this position are physiotherapists and speech therapists, both of which have evolved from branches of education, physiotherapists from physical education and speech therapists from educators and lower cycle teachers.

During the last decade much training has been funded and delivered by international NGOs, sometimes associated with their home countries' Universities and officially recognised national training bodies, sometimes on a rather more *ad hoc* basis and occasionally of rather doubtful standards. The result has been that professional practice in areas that have not been developed to a fully professional level within Albanian higher and professional training institutions is immensely varied. This was evident during our visits to institutions, schools and NGOs and was a source of concern to their Directors and to the senior officials that we met in the Ministries of Education and of Labour and Social Affairs. Both Ministries recognised that Albania itself would increasingly have to ensure initial and continuing professional development.

The discussion in this Section of the report will look at four key aspects of professional training:

1. increasing disability awareness and competence in well-established professions that have some importance to children with disabilities but not a full-time commitment,
2. developing specialist qualifications for professionals qualified at varied levels who have a major – sometimes full-time - in-put to children with disabilities,
3. developing qualifications in professional areas that are important to children with disabilities but that are not yet fully functional as professions, and
4. the importance of sharing training where appropriate and practicable.

Increasing disability awareness and competence in well-established professions that have some importance to children with disabilities but not a full-time commitment

Of the professions and other workers listed above, only prostheticists would expect from the beginning of their training to be involved only with disabled people. We did not meet any prostheticists during our study or visit the Military Hospital in which they are based. However, we understood from discussion with medical personnel at the National Centre for the Development and Well-being of Children (formerly the Dystrophic Hospital) which works closely with the prostheticists that the professional training provided by Swiss Caritas had been of a very high standard. More than forty children have been fitted with prostheses.

Of the four other now well-established professions that work with children with disabilities – doctors, dentists, social workers and psychologists – professional routes post qualification spread widely and many doctors and dentists, for example, will only work with people with disabilities incidentally, as individuals within a much wider community. Nonetheless, it is important that they should be sensitive and competent in their professional handling of such encounters. We recommend that all initial degrees in both medicine and dentistry contain required elements of general disability awareness and of more specific implications for professional practice in working with children and adults with disabilities (Recommendation 96). It was also apparent to us, as discussed in the previous Section of the report, that there was a shortage of paediatricians and of dentists with more in-depth specialisation in children with disabilities. We recommend that the Ministry of Health, in collaboration with relevant University Faculties, encourages emerging doctors and dentists towards such specialisms (Recommendation 97).

It was apparent that most Social Workers felt that their courses had not given them a sufficient depth of knowledge and understanding about people with disabilities, yet much of their subsequent employment was actually concerned with people at socio-economic disadvantage including disabled adults and disabled children and their families. We recommend both that Social Work positions which involve intensive work with children with disabilities should be filled by graduate Social Workers and that their courses should have a more substantial theoretical and practical in-put relating to children with disabilities (Recommendation 98).

It seems that, currently, psychology courses have anticipated that many of the graduates on the four year degree courses will in fact eventually work to some extent with children with disabilities and their course content and practical placements reflect this. We further recommend that in all in-puts to all professional graduate courses, a social model of disability be presented but that a more detailed knowledge of specific conditions is subsumed within this model and that a holistic approach to assessment of abilities be adopted (Recommendation 99).

Developing specialist qualifications for professionals qualified at a varied level s who have a major – sometimes full-time - in-put to children with disabilities,

We agree wholeheartedly with the succinct criteria suggested by the Ministry of Labour and Social Affairs for people caring for and developing children with disabilities in a professional capacity. It was suggested that they should be well educated, communicative and able to make good emotional relationships with the children in their care. We also believe that professional training/education makes a very substantial contribution to such a profile and that professional education/training should not be a once in a lifetime process but rather a continuing process. There appear to be three main groups of personnel involved in educational and developmental programmes for children with disabilities; auxiliary staff, educators and teachers.

The first group of staff are largely unqualified auxiliary staff who work as general practical assistants but are not perceived as educators. Some may be dormitory staff in residential schools, or caretakers, drivers, domestic workers etc. Their own educational attainments are probably very varied, as are their roles. We would recommend, however, that all workers in any establishment whether of the Ministry of Education, Ministry of Labour and Social Affairs, NGO or private, should have some basic induction training that covers issues such as disability awareness and children's rights as well as an introduction to their specific role and that this training should be the responsibility of the Director although a simple national package for the disability awareness and child rights elements could be prepared by ADRF and the Child Rights Centre of Albania (CRCA) (Recommendation 100). We would also suggest that, as such posts sometimes attract people who have not fulfilled their own educational potential, employers should facilitate their further education and qualification where this is wanted by the individuals concerned (Recommendation 101).

The second group of personnel are the Educators, some of them qualified through four-year secondary pedagogic schools. Others are not qualified in this 'official' route but may have other academic or vocational qualifications. During our visits we found artists, historians, musicians, geographers, nurses and several qualified teachers employed as educators. Many had received various kinds of training from international and Albanian NGOs in working with children with disabilities, usually through short courses. Educators work within all Governmental Institutions for children with disabilities, special schools and classes, residential developmental and day centres, generally holding a more central role in the latter two than in the former where teachers have the key professional position. In Section 14 we referred positively to the course currently being developed by ASED, the Swiss University of Friburg, the Ministry of Labour and Social Affairs and Vlora University Pedagogy Department although we did not have full details of its contents. However, it appears that the Ministry of Labour and Social Affairs aims to have a more fully and appropriately qualified staff for its centres and we welcome this.

In Section 6 of the report we explored the overlapping responsibilities of the two Ministries in relation to children with disabilities and suggested that, at some time in the future, the Ministry of Education might take over the responsibility for all developmental and educational programmes for children with disabilities as is the usual practice in most European countries. We would suggest, in that case, that educators who wished to do so would also have the opportunity to become Resource or Specialist Resource Teachers (see later in this Section), possibly i) by means of a short transition course for those with appropriate general educational qualifications, followed by ii) undertaking the relevant specialist course (Recommendation 102).

The third group of personnel involved in the education of children with disabilities are teachers, both in special schools and classes and in mainstream schools where significant numbers of children with mild to moderate disabilities are already included. Our understanding is that any training in mainstream schools for this role has been more recent, relatively brief and associated with the various pilot

inclusion projects (ADRF-Nano 2002). We recommend that *all* teachers and educators undertaking initial training in any pedagogical secondary school or pedagogical or other University should receive an introduction to the inclusion of children with disabilities/special needs as an integral part of their course. The development of IEPs and of differentiation strategies should be emphasised. A national package of teaching and learning materials should be developed and made available to the various training institutions to support students and lecturers who may themselves have little or no experience in this area (Recommendation 103).

With the national trend towards Inclusive Schools (Section 16) there is, as we recommended in Section 16, a need for each school to have a Resource Room and a Resource Teacher. We also recommended that some schools should have an attached Special Class for children with more severe and complex disabilities and that it should be staffed by a Specialist Resource Teacher or Teachers (depending on numbers of children and levels of disability) working with educators. We have drafted role specifications for these teachers below.

“Resource” Teachers’ role would include:

- ❖ keeping a record of all pupils in the school who have special needs, especially those with mild/moderate mental disabilities but also any with sensory or physical disabilities or other specific difficulties such as dyslexia and ensuring regular reviews of their progress and of IEPs,
- ❖ being responsible for liaison with their parents and with other non-school professionals such as medical and social services, in collaboration with the school social worker and psychologist (if any), class and subject teachers, and Director,
- ❖ being involved with the Director and the Local Education Authorities about the admission or (exceptional) transfer of pupils with special needs,
- ❖ supporting other teachers in their work with children with learning difficulties by providing the teachers with relevant information and advice on curricular and pedagogical matters relating to individual children with special needs,
- ❖ providing additional in-class help by team teaching where other teachers and pupils with special needs would benefit from this,
- ❖ providing some limited specific tutorial help for pupils with special needs out of class in the common Resource Room and being responsible for the organisation and use of the resource room,
- ❖ ensuring the availability of relevant specialist resources to pupils and/or other teachers,
- ❖ helping class and subject teachers, parents and pupils themselves develop IEPs for those pupils whose work pace and/or programme content varies substantially from those of classmates,
- ❖ helping class and subject teachers to ensure that these pupils are still socially fully part of their class, and
- ❖ collaborating closely with the Specialist Resource Teacher and other Special Class staff if the school has a Special Class.

Specialist “Resource” Teachers’ role would include:

- ❖ acting as Head of the Special Class and as leader for the Educators and auxiliary staff also working with the pupils of the Special Class,
- ❖ being responsible for liaison with parents and with other non-school professionals such as medical and social services, in collaboration with the school social worker and psychologist (if any), and Director,

- ❖ being involved with the Director and the Local Education Authorities about the admission or (exceptional) transfer of pupils with special needs,
- ❖ working with other teachers, including the school's Resource Teacher, to identify opportunities for inclusion of the Special Class pupils, by providing the teachers with relevant information and advice on curricular and pedagogical matters relating to these pupils,
- ❖ working directly with the pupils in the Special Class and supporting other Special Class staff in working with the pupils.
- ❖ ensuring the availability of relevant specialist resources for pupils and other staff in the Special Class, and
- ❖ helping educators, parents and pupils themselves develop IEPs for **all** pupils.

Within special schools and classes very little training indeed has been undertaken other than internally within individual establishments, sometimes by international NGOs. The *Normative Dispositions* (Albanian Government 2002a) make it plain that entry to special school and class teaching should be by competitive interview, that such teaching is for 'expert teachers' and that they should be paid an additional allowance for this work. However, it is hard to move into a sometimes significantly different pupil context and truly be 'expert' without additional training.

We consider that there is a need for a differentiated specialist qualification for teachers working with children with disabilities, in mainstream and in special settings, and that this qualification should be a Graduate Diploma rather than at post-graduate level. While a post-graduate award might eventually be desirable we consider that there are neither currently sufficient written resources nor lecturer and research personnel to staff a post-graduate award in Albania. The demands of a post-graduate award might also be heavy and deter some candidates who should do it from undertaking it. Educators within special schools and classes might also participate in this programme but perhaps with some differentiated tutorials and a more practical rather than written assignment to qualify for a Certificate rather than a Graduate Diploma.

Such a course could be one year full-time but we believe that full-time study is too expensive to fund nationally and too difficult practically and domestically for mature qualified teachers to undertake. We recommend therefore that there should be a choice of modular courses that could be taken by part-time semi-distance study over a period of three to four years that would lead to an award as a qualified general Resource Teacher or as a qualified Specialist Resource Teacher. The latter would have a choice of four specialisms; in Deaf Education, Visual Impairment/Blind Education (these would also be taken by potential peripatetic support teachers for children with sensory impairments based at the two Special Schools), Physical Disabilities & Medical Conditions and Mental Disabilities & Complex Disabilities. The last group would also address more complex communication difficulties including Autism. (We have some reservations about the viability of a separate specialist programme for Physical/Medical conditions but we are including it for the purposes of discussion at this time.) There would be some shared modules across different specialisms and it might be possible for teachers not undertaking the full awards, or even other professions, to undertake individual modules. Teachers who completed the Graduate Diploma, and Educators who completed the Certificate, could add additional modules to their qualifications to widen their expertise.

The focus of each programme would be broad in age range, from kindergarten to the upper cycle of eight-year schools and, possibly, secondary education. Educational aspects would address pupils with disabilities from mild to the most severe. Educational contexts would cover from full inclusion in mainstream to special school.

The broad aims for this cluster of programmes would be as follows:

- ❖ to develop and apply appropriately knowledge, skills and attitudes relevant both to the education and development of the pupils with whom the teachers work
- ❖ to be able to work co-operatively and in consultancy with colleagues, other professionals, families of pupils and pupils themselves
- ❖ to reflect critically on theory and practice and to explore issues in the implementation of educational and social principles and ideals
- ❖ to be active in continuing professional development of self and of others within the particular field of specialism
- ❖ to develop a commitment to the valuing of all pupils as of equal worth and to enabling their optimal development

A suggested framework, with the five routes in columns, is drafted below for discussion but other frameworks could be developed. Each module would have its own pack of learning materials to be worked through at home and each would also require about two weekends or four days of meetings in addition to time spent in home-based study.

<i>Programme of Graduate Diplomas for Resource and Specialist Resource Teachers and of Certificate for Educators in Mainstream and Special Schools and Classes</i>				
Resource Teacher	Specialist Resource Teacher (Deaf Education)	Specialist Resource Teacher (Visual Impairment/Blind)	Specialist Resource Teacher (Physical Disabilities & Medical Conditions)	Specialist Resource Teacher (Mental Disabilities & Complex Disabilities)
Collaboration and Consultancy: Working with Others (Colleagues, professionals and families)				
Social Justice and Inclusion: Disability, Society and Inclusion				
Teaching and Assessment for Effective Learning	Deaf Studies	An Introduction to Blindness & Visual Impairment	An Introduction to Physical Disabilities & Medical Conditions	The Range of Mental Disabilities and their Educational Implications
Developing Appropriate Curricula and IEPs with Colleagues	Audiology	Assessment & Planning: Development of IEPs	Teaching & Assessment for Effective Learning and IEPs	Assessment of Potential and Mental Disabilities
Supporting Pupils with Dyslexia and/or Communication Difficulties	Language and Communication (Sign Language competence required)	Strategies for Teaching (Braille competence required)	Psychological Implications of Physical Disability/Medical Conditions	Teaching Strategies and Severe & Complex Mental Disabilities
Supporting Pupils with Sensory and Physical Disabilities	Curriculum, Pedagogy & Assessment 1: Differentiation and IEPs	Blind & Vis. Imp. Pupils with additional disabilities	Staying in Touch: Coping with Discontinuity in Education	Communication & Pupils with Severe & Complex Mental Disabilities
Support and IT	Curriculum,	Specialist	Uses of IT and	Managing

	Pedagogy & Assessment 2	Technology and Blind Pupils	Working with Therapists to optimise useful function	Challenging Behaviours in Pupils with Mental Disabilities
<i>Either</i> a Research Project within own school (more experienced teachers) <i>or</i> Supervised Practice within own or other school (less experienced teachers)				

These programmes would require to be delivered, ideally, by specialist staff of standing and experience. It is likely that they too would require some prior development. However, there seems to be no alternative but to draw some of the teaching and learning materials for each pack of module materials from international sources. We think that the development and implementation of such a programme, with implications for both mainstream and special schools and classes, require substantial investment. We recommend that this matter be discussed by key personnel in the Ministry of Education, lecturers in pedagogy from the various Universities, Education Authority Directors for Special Needs, and Directors of schools. If approved, a research and development strategy should be planned and a potential Centre for Special Needs Teacher Development should be identified, probably within Tirana University (Recommendation 104).

Developing qualifications in professional areas that are important to children with disabilities but that are not yet fully functional as professions

Swiss Caritas undertook the training of four physiotherapists for the National Centre for the Development and Well-being of Children but they appear to be the only four more fully trained paediatric physiotherapists in Albania. The development of children with physical disabilities such as cerebral palsy and of children with a range of complex disabilities – many doubtless at home without services – depend on building and maintaining function. Far too many children with severe and complex and even moderate disabilities actually develop further physical disabilities as a result of poor posture, muscular contractions and lack of appropriate exercise. This in turn leads to poor health and eventual organ failure. The life expectancy of people with physical disabilities who could be healthy is actually very much less than that of other people. Physiotherapy is also essential in the lives of some children with acquired injuries as the result of accident or illness and for some children with chronic or deteriorating conditions such as muscular dystrophy and cystic fibrosis. Physiotherapists are often used as advisers in relation to mobility aids.

Although we appreciate the difficulty in funding such a venture we would recommend setting up a full national three or four year degree course for professional physiotherapists. We would hope that some classes might be shared with medical students and (to a lesser extent) with PE students to reduce some of the costs in establishing the course. We would also suggest that their training must include working with children with physical and complex disabilities and that the course should develop their critical knowledge of aids to mobility (Recommendation 105).

We met several speech therapists in Centres and Schools and also discussed their role with some Special School and Centre Directors. It seems that this profession has evolved from early education courses and is mainly concerned with speech production. Work often seems to be undertaken with children on a one-to-one basis, an extravagant use of scarce personnel resources unless the outcomes merit this individual attention. We do not underestimate the importance of high quality speech therapy but consider that practice needs further development in Albania. Internationally, speech and language

therapy has become much more concerned with communication and deeper language issues and with children with very serious problems such as aphasia, and even with feeding of children with, for example, cerebral palsy whose jaw and throat control is affected. Albania does not have such therapists currently and does not have even a core staff who might generate some dissemination of useful advice to teachers, nurses and parents.

We do not think it practicable at this time to set up a training programme for speech and language therapists, However, if Government funding, or Donor or NGO sponsorship could be found, we would suggest that two very able and interested language students be identified for training abroad to develop a knowledgeable professional nucleus in this area and to act as advisers (Recommendation 106). We suggest language students for two reasons; they themselves will have an interest in and appreciation of communication, and they would also be able to study abroad more easily. Full degree courses normally last four years in European countries.

We would also suggest that two other significant professions should also be treated in a similar way, by sending two appropriate people abroad. The two professions are those of Paediatric Audiologist for deaf children and Mobility Training Instructor for blind children. We highlighted the absence of these key professions in Section 17. Again, we believe that this would be an appropriate NGO sponsorship or Donor project and that personnel should be selected if possible from those already working with deaf and blind children (Recommendation 107). In both cases one individual should be sufficient and these courses can be as short as six months, depending on the individual's previous experience and knowledge and the course selected.

One of the most valuable professions to children and adults with disabilities is that of Occupational Therapist. Their role is to advise on ways of making daily living more manageable by identifying appropriate aids and adaptations and easier strategies for the individual to be more independent. At this stage in Albania's development we believe that it would not be expedient to introduce a new profession. We have already suggested in Section 13 on Social Services that Social Workers should try to cover some of this role, especially in relation to managing life at home. We have also suggested in this section that physiotherapists should develop critical knowledge of aids to mobility in their training.

The importance of sharing training where appropriate and practicable.

As Albanian professional training to work with children with disabilities/special needs begins to develop we hope that it will be an integral part of the 'joined up working' that we identified in Section 4 as being so important if the lives of children with disabilities is to improve. While individual Ministries, Institutions and training organisations (national, NGOs and private) will undoubtedly plan programmes to meet particular needs known to them, we hope that this will be done openly and in consultation with other training providers and especially with the knowledge of the National Group that might be set up to develop a National Strategy for Children with Disabilities (Section 4, Recommendation 7). We suggest that a national Register of Professional Training for those working with children with disabilities be kept, possibly by the Albanian National Monitoring Centre for Disability or other appropriate agency, in order to avoid the waste of overlaps and gaps in training provision and to facilitate the sharing of training (Recommendation 108). Shared training has not only economic advantages, it also enables greater inter-professional understanding and facilitates future collaboration.

This Section has focussed on increasing professionalism but it is important to emphasise that this is not simply about professional knowledge and efficiency. We would also like to emphasise that while many

families of children with disabilities do, of course, hope to find knowledgeable professional support, they also hope to find professionals who relate to them with human understanding and warmth and that value their child. While some professionals already show such humanity it is important that interpersonal skills training is embedded in all professional training courses (Recommendation 109).

Of course I do not really know my doctor as I do my family or my neighbour but I do think of her as a friend because she is welcoming and positive to my son and me. I can ask her about anything that is worrying me and she will try to help.

(Mother of boy with severe and complex disabilities)

I like my teacher, she smiles and explains things to us.

(Girl (12) with moderate mental disabilities)

Report Conclusions

Throughout this report we have tried to hold true to the principles of the UN Convention on the Rights of the Child because *all* its Articles apply to *all* of Albania's children. They apply just as much to the child with multiple disabilities, living at home in an isolated village with his family and totally without any additional help or services of any kind, or in a residential institution, as to the healthy child of sophisticated and influential parents, living in central Tirana and heading for University and independent life.

We have tried to suggest ways of closing gaps in systems and in provision that currently ensure that children with disabilities and their families experience multiple forms of disadvantage. Angry, sad and critical feelings have been voiced, as they should. Many children with disabilities have suffered throughout their lives and their families have demonstrated their love and commitment to their children in the most deprived and painful circumstances. This commitment has lasted not over a few weeks or even a few years but over their children's complete life-times. For many families there has been no help of any kind from beyond the family itself.

However, improvements have taken place, although they are not sufficient and their emergence is far too slow. We have noticed positive developments, met committed professionals, including well-educated and qualified young people who have chosen to stay in Albania and contribute to its more humane society. We hope that our report has not just highlighted suffering and need but that it has allowed children, parents and professionals to express their appreciation of some of the many positive things in each other.

All over the world there are crises and it would be wrong to suggest that any child, any nation, is more worthy of help than another. However, we believe that Albania is now at a time when external help would be effectively utilised because Albania's internal systems are being improved, links are being made with supportive structures in Europe, and young people have been, and will continue to be, educated and trained to take up their responsibilities in society. Finally, we hope and believe that there is greater awareness of the need for a just society that values *all* of Albania's children.

There are constructive ways ahead for Albania's children with disabilities and their families but they will take time, energy, creativity, stamina, optimism, 'joined up working' and money from within the country and also from outside. Parents, children and many professionals are already committed to a better future – we hope that the Government and its agencies, international and Albanian NGOs and donors of all kinds will keep faith with them and enrich Albania's future as a whole country.

Collated recommendations arising from the report organised by Sections of the report (in which they were first expressed)

Key:

G Recommendations for consideration by the Government and its Ministries

NGO Recommendations for consideration by one or more NGOs

D Recommendations thought to be especially appropriate in whole or in part for a Donor project

LA Recommendations for consideration by Local Authorities

*** Asterisked recommendations are thought to be particularly important

1. Introduction

NGO & G Recommendation 1. It would be useful to have an overview of provision, outstanding needs and current initiatives in relation to children with social, emotional and behavioural difficulties of a more severe nature, i.e., children who present with severely disturbing and disturbed behaviour directed at self or others, children who are involved in substance abuse, children who are involved in crime or are at risk of becoming so, children who present more persistent and extreme challenging behaviour in school.

2. Albanian society and disability

***G Recommendation 2.** The Government should consider further practical and financial means to supporting families with disabled children to ensure that caring for children within the family continues to be the first choice of families and that it does not place an unreasonable burden upon them.

***NGO & G Recommendation 3.** ADRF, other competent agencies such as the Pedagogical Institute, and the Ministry of Education should collaborate to develop further ADRF's training module on developing inclusive schools and ensuring that it is delivered across all of Albania's Kindergartens and Basic Schools.

NGOs & D Recommendation 4. Contemporary media and public education resources should be focussed on presenting images of children with disability and their families that engage empathy and increased public involvement rather than pity. Public figures should, model *normal and inclusive* ways of being with children with disabilities. Up-beat poster campaigns and TV Spots are highly appropriate Donor projects.

3. Ethnic and linguistic minority issues

NGO & D Recommendation 5. ADRF should be encouraged to produce a core selection of their public and parent information leaflets in minority languages and in alternative forms such as Braille or video clips. This would be an appropriate Donor project.

G Recommendation 6. The inter-relationship between disability, minority status and equity in access to services for children should be examined (See also Recommendation 7 in the Section below).

4. The Albanian Government and disabled children

***G Recommendation 7.** There is a need for a forum bringing together Education, Health and Social Services, GOs and NGOs, children's rights or advocacy groups and parents' associations to establish a National Strategy for Children with Disabilities that ensures optimal developments for the benefit of *all* children with disabilities.

***G Recommendation 8.** Disability should be taken as far as possible out of party politics with responsible administrative officials in Ministries being allowed sufficient stability in post to develop knowledge and expertise and to ensure continuity in developments.

5. The role of Non-Governmental Organisations

***G & *NGO Recommendation 9.** The Government and larger NGOs should consider together ways of enabling NGO activity in the least accessible parts of Albania to support children with disabilities and families there, A peripatetic research and development officer could be contracted short-term to work with Local Authorities to map possible projects in these areas.

G & NGO Recommendation 10. Business-NGO partnerships could be the focus of a sub-group of the proposed children's strategy committee or of the over-executive group for both child and adult strategy groups and would involve business managers directly. Both tax concessions and ethical advertising should be discussed.

LA Recommendation 11. Local authorities should keep a list of local NGOs and Parent and other Associations and facilitate the sharing of existing premises that offer opportunities for increasing levels of inclusion in the ordinary local community

G Recommendation 12. The Government or relevant Ministry could be asked to subsidise 'expenses only' mentoring visits of approved, experienced practitioners to support new or struggling NGOs and Associations working to develop important resources for children with disabilities.

6. Efficient cover of work to be done: gaps and 'overlap' in activities and roles

***G Recommendation 13.** We recommend that relevant officials of the Ministry of Education and the Ministry of Labour and Social Affairs have regular meetings to ensure that policy developments in relation to the education/training/occupation of children with disabilities harmonise. One possible *longer-term* scenario they should consider is that:

- ❖ the Ministry of Education take over responsibility for the educational / developmental programmes of *all* children, ideally mainly in partnership with Local Authorities within mainstream schools, but with some special school and special class provision as necessary, and that

- ❖ the Ministry of Labour and Social Affairs assume responsibility for residential accommodation for all children with disabilities who require this (but *not* in schools with attached residences such as the Schools for Blind and for Deaf children which would remain the responsibility of the Ministry of Education), and for all adult specialist day and residential provision.

***G & NGO & D Recommendation 14.** We suggest that the Ministry of Labour and Social Affairs should plan optimally normalised living in family size and type home settings for adults with severe mental or complex disabilities. **No further medium or large residential institutions should be opened,** Wherever possible, adults who have lived together over some years should be grouped together in any re-housing exercise and those who have any family connections or friendship contacts should be located near them.

***G Recommendation 15.** We recommend that the Ministry of Health clarifies any overlaps between the National Centre for the Development and Well-being of Children and the Department of Mental Health and, where the Centres continue to function with some overlap, facilitates collaboration between the two Centres.

7. Numbers of children with disabilities and data collection

***G Recommendation 16.** We would suggest that the Government bodies that plan the Albanian Census should include questions on disabled family members and that they should draw on the experience of other countries to do so

***G Recommendation 17.** We recommend that *every* child age five should be registered at his/her local school and that any child identified with disabilities/special needs at that time should have their details recorded and sent to both the local education authority Director for Educational Support for onward transmission to the Ministry of Education, and to the local office of the Institute for Social Insurance, for onward transmission to the Ministry of Labour and Social Affairs.

***G Recommendation 18.** We also recommend that children who are refused placements to any Residential or Day Centres by the central admissions office of the Ministry of Labour and Social Affairs, or are refused entry to Special Schools, should also have their details copied with reasons for refusal to local Social Services and Education Authority offices and to the Ministry of Education. Local offices should follow up these children and try to ensure some local placement.

***G & GO & NGO Recommendation 19.** We recommend strongly that a working group comprising representatives of the Ministry of Education, Ministry of Labour and Social Affairs, the National Monitoring Centre for Disability, the Ministry of Health, the NGOs MEDPAK and Ndhimoni Jeten and at least one computer database expert be convened to plan the identification of children with disabilities and related data-gathering and to detail its costing, specification and timeline.

8. 'Invisible' children

LAs, NGO & D Recommendation 20. We recommend that LAs, NGOs and donors think of original ways, exploiting modern technology and developing de-centralised outreach services, to enable children who actually need to be in their homes, hospitals or in other 'enclosed' provision (for example, children with very serious illness or deteriorating conditions) and their families to feel better supported and better linked to the mainstream of life.

G & NGO Recommendation 21. We recommend that, as further service provision for children and young people and other developments are planned in Albania, every effort should be made to prioritise currently 'invisible' children with disabilities and other special needs who could and should be included and to ensure by legislative and educational means that the community is one that welcomes their emergence.

9. Families of children with disabilities

***G & NGO & LA Recommendation 22.** We suggest that all programmes that seek to offer parents respite or to start the process of inclusion should ensure that:

- ❖ the transfer of care is very gradual and within the control of the parent,
- ❖ parents may stay with the child in the respite or kindergarten/school situation until the child is fully settled,
- ❖ respite could be offered in the family's own home using personnel already known to the family,
- ❖ whenever possible there should be continuity of personnel involved,
- ❖ a named person of the care establishment/service, of the parents' choice, should be freely contactable by the parent.

NGOs & D Recommendation 23. . We recommend that supported holiday opportunities be found for all families with children with more severe disabilities from time to time.

***G & D Recommendation 24.** We recommend that disposable nappies be provided at a reduced cost to parents with children with severe disabilities who are incontinent over the age of six.

10. Siblings

***G Recommendation 25.** We suggest that families should, where possible, be given clear information on genetic probabilities of familial incidence, if any, in siblings and in subsequent generations.

11. After childhood – adult occupation and care

***NGOs & G & D Recommendation 26.** We recommend strongly that an NGO or NGOs, possibly with Donor support should commission a consultant's report on prospects both for supported open employment and for part-special workshops (with a proportion of mentor/trainer non-disabled workers) and that some pilot programmes are established in collaboration with Employment Offices.

***G & LA Recommendation 27.** We recommend that vocationally-orientated secondary education be developed for young people with mild mental disabilities and for young people with physical and sensory disabilities. This should be in inclusive or semi-inclusive settings where possible.

12. Financial support for families

***G Recommendation 28.** We recommend strongly that the Individual Disability Benefit system should be radically revised at the earliest possible date and that, before doing this, those responsible

should look at systems used elsewhere to identify improvements that could be applied within the cultural, geographic and economic contexts of Albania.

NGO & G & LA Recommendation 29. NGOs, social workers attached to the local offices of the Social Insurance Institute, ADRF and national media should publicise the (revised) support system in a variety of non-stigmatising and accessible ways to increase uptake of eligible claimants and social workers and NGOs should support claimants in the process.

***G Recommendation 30.** Children with severe lifelong disabilities or life-threatening or shortening conditions should be medically certificated to that effect and should not be required to undergo annual examination. An official form verifying continued life could then be presented at the KMCAP tribunal.

13. Social services and social support at critical times

***G & NGO Recommendation 31.** We suggest that social workers should be involved in the identification of children with disabilities in any data-gathering or census exercise.

***G Recommendation 32.** We recommend that Social Workers should have a broad personally supportive role with families who have children with disabilities and particularly at critical periods of the child's life.

***G Recommendation 33.** We recommend that at any later stage, where a child with disabilities is placed in a residential institution, a social worker should be appointed as a public guardian *pro bono* (for their good). Such a role is not located within the institution in which the child is placed but rather stands apart from it and acts only in the interest of the child, their client, and advocates on his/her behalf, visiting about four times a year, unannounced.

***G & LA Recommendation 34.** We suggest that, in the absence of Occupational Therapists, social workers should assume responsibility in consultation with physiotherapists for advising parents of children with disabilities about mobility and other aids to daily living, and assist the family to obtain them.

14. Residential Developmental Centres & Day Centres

***G & NGO Recommendation 35.** We recommend strongly that approaches to de-institutionalisation of children with disabilities, including adoption, fostering and smaller family-type homes be developed.

***G & NGO Recommendation 36.** We recommend strongly that all staff working with children with disabilities in all kinds of Centres, Special Schools and Special Classes undertake training that enables them to work appropriately and optimistically with children with more severe and complex disabilities.

***G Recommendation 37.** We recommend that conditions of work be established in all Centres that enable staff to work appropriately and developmentally with the children in them. These conditions must be enhanced where there are children with more severe and complex conditions by, for example, increasing the staff to child ratio.

***G & LA Recommendation 38.** We suggest that the development of good parent-staff relationships should be a focus of staff development and that Centres' (and Schools') practical arrangements for receiving parents should reflect a welcoming approach.

***G Recommendation 39.** We suggest that the introduction of contracts between Centres and parents might be an appropriate research project for a final year or post-graduate social work or psychology student.

***G & NGO Recommendation 40.** We recommend that the situation of the remaining children with disabilities within State and private/NGO orphanages should be explored and monitored by the Ministry of Labour and Social Affairs and appropriate plans developed for them that lead to family or family-type care and inclusion.

***G & LA Recommendation 41.** Developmental Centre residents should be welcomed in their neighbourhood and beyond and neighbours should be encouraged to be involved with Centres. Local authorities and neighbourhood associations should be actively involved with Centres in seeking inclusive and 'normal' ways of ensuring this.

G Recommendation 42. Centres' residents and accompanying staff should have a small budget to ease their participation in the local community and to avoid being perpetual objects of charity from others.

***G Recommendation 43.** We recommend that material and humane standards in Residential Development Centres continue to be both internally evaluated and subject to external inspection and support.

***G Recommendation 44.** We recommend that Centres (and Schools) find ways of keeping and updating records and IEPs, and of implementing IEPs, that enable them to be useful. However, they should not be such a heavy task that time, that should be spent by staff in working with the children with disabilities in their care, is spent in administrative tasks. IEPs in Day Centres (and in schools) should be shared with families in terms of planning and implementation.

15. Education

***G & LA Recommendation 45.** We recommend that children with disabilities are considered at every stage of the national efforts to achieve 'Education for All'.

***G Recommendation 46.** We recommend that the Ministry of Education ensure that each Local Authority appoints a Director for Special Needs who will have responsibility for pupils with special needs resident within the Authority, for Special or Resource classes in Mainstream Schools and their teachers and, jointly with the Ministry of Education, for Special Schools located within the Authority to ensure that all pupils with special needs within any authority receive appropriately supported education.

***G & LA Recommendation 47.** We also recommend that children with disabilities or medical conditions should only be refused entry to their local school, or be 'sent away' from any school in which they have enrolled, if the Director of the School has sent all documentation to the Local Authority Director of Educational Support, consulted with her/him, and been given consent for the action.

16. Inclusive schools

***G & NGO Recommendation 48.** We suggest that both the Local Authority Directors of Special Needs and Directors of Schools be prioritised for professional development in inclusion.

LA Recommendation 49. We also recommend that each larger Local Authority establish an Education Support Centre to act as a display centre for teaching and learning resources, a base for in-service activities and a base for any peripatetic support staff. Groups of smaller neighbouring Authorities might develop a shared Education Support Centre.

***G Recommendation 50.** We recommend that the Ministry of Education be asked to set a time-scale for their implementation of the Options for teachers implementing inclusion of disabled teachers set out in the *Normative Dispositions*, if need be reducing the Option benefits initially to facilitate earlier part-implementation. There should also be resolution of how the Options should apply to teachers in the upper cycle of 8 year schools.

LA Recommendation 51. Larger or smaller but isolated schools, and clusters of two or three smaller neighbouring schools, should establish a Resource Base that would have multiple roles. Some children with mild and moderate disabilities could be withdrawn there for additional help from the Resource Teacher, as could very able pupils who need extension studies. The Resource Base might also be where computers, once affordable, could be located and other electronic equipment.

***G & LA Recommendation 52.** We recommend that Special Classes should be established in some 8 year schools for *children with severe and complex mental disabilities* as they come into schools, not as currently, for pupils with moderate to severe disabilities. Special Classes would be authorised by the Ministry of Education but the Local Authority would have responsibility for in its day to day running. Staffing would include a Specialist Resource Teacher and trained educators at a level that reflected the number of children in the classes and their degrees of disability. Children with moderate disabilities should be within mainstream classes with IEPs and some support in class and Resource Bases.

***G & LA Recommendation 53.** Children with physical or health-related disabilities but without mental disabilities or with only mild to moderate mental disabilities should be included as far as possible in mainstream classes. Those who are unable to attend school should receive some home-based education.

***G & LA Recommendation 54.** There is a need to establish a programme of physical access adaptations to at least one school in each area initially. Where a child with a physical disability has to go to a school that is not his/her local school, the Education Authority should subsidise the costs of transport.

***G & LA Recommendation 55.** Resource Rooms, Special Classes and good physical access should be integral to the planning and building of all new eight year schools.

*** LA Recommendation 56.** We recommend that no child should spend all of his or her time in a Special Class or in a Resource Base and that, whenever possible, he or she should spend optimal time with mainstream classes, including being registered with age peers in a mainstream class.

17. Special classes and schools

***G & LA Recommendation 57.** We see the provision of transport for pupils with disabilities to special schools, and – in the case of children with physical, sensory or health-related disabilities – to mainstream schools, as a priority.

G & LA Recommendation 58. We recommend that Special Schools seek partner mainstream schools (and that mainstream schools seek partner Special Schools) to explore a range of links, some of which could relate to sport and recreation and aesthetic subjects, but that might also involve project work and curricular co-operation.

***G Recommendation 59.** We believe that, while age cannot be the sole consideration in grouping pupils for their education, it must be an important factor for pupils' self-esteem. We consider that 'attainment grouping' across ages should only be used for short occasional lessons and not for the formation of classes.

***G & LA Recommendation 60.** We would like to see practice in collaborative planning of IEPs between teachers, parents and children improving.

***G Recommendation 61.** We recommend that the Ministry of Education establish agreements with parents of children attending the Schools for Blind and Deaf Children that they must take their children home for one weekend in four as a minimum or, if possible, more often. Transport vouchers for children and for an accompanying adult should be funded by the Ministry of Education

G Recommendation 62. We also recommend that both the Schools for Deaf and for Blind Children have an attached social worker, primarily to work on the area of home-school liaison but also to work with the schools towards these children's and young people's greater societal inclusion

***G Recommendation 63.** We think that all staff in the School for Blind Children, sighted and blind would benefit from staff development in differentiation, the preparation of IEPs and their implementation in classes of mixed ability.

***G Recommendation 64.** We would recommend that a national approach to the provision of appropriate detailed optical testing and free supply of spectacles and other low vision aids to children be prioritised after the present broad national screening. This is likely to bridge both the Ministries of Education and of Health.

***G Recommendation 65.** We recommend that, as children with visual impairment are identified, the nature of each child's condition should be assessed professionally, particularly in terms of the likelihood or otherwise of retaining educationally useful vision, and that this should be taken into consideration when recommending educational placement.

***G & D Recommendation 66.** The Government should also take advice and obtain supplies of low vision aids to support inclusion of children with non-deteriorating visual impairments who have usable vision and who could be placed in mainstream schools.

G Recommendation 67. We believe that, in the longer-term, children with visual impairments who have other severe disabilities should *not* attend the School for Blind Children but should, rather, attend a local Special Class with specialist support.

***G Recommendation 68.** Support for children who are blind or visually impaired in inclusive settings, their Specialist Support Teachers, Class teachers, Educators and parents, should be provided by a Peripatetic Specialist Teacher (Visual Impairment) based in the School for Blind Children

***D & G Recommendation 69.** We recommend that a Donor be sought to fund a member of the Special School for Blind Children staff to train in the use of specialist computer software and to fund the purchase of relevant computer hardware and software and of low vision aids for the school.

***G Recommendation 70.** We recommend that a future scenario is discussed in which the School for Blind Children would be not only a school but also a resource base for outreach services to blind and visually impaired children in other locations, have a non-residential pre-school facility, residential facilities as now for 6/7-18 year olds and teaching for 3-10 year olds. The upper cycle of the school for 10-14 year olds might be linked closely to a nearby mainstream school so that pupils from both schools could benefit from greater inclusion.

***G & NGO & D Recommendation 71.** We recommend that another special school for deaf children should be opened in Shkodra or Vlora in order to offer more geographic proximity for children and families and to include more deaf children who are currently not within education.

***G Recommendation 72.** We recommend that both the existing Special School for Deaf Children and the new Special School should include children with mild to moderate mental disabilities as well as the current population of more able pupils and that there be more differentiation and use of IEPs.

G Recommendation 73. We recommend that both Special Schools for Deaf children should develop day kindergarten facilities, and outreach support teams for children with mild hearing difficulties in mainstream schools and kindergartens or other Special Schools (for children with special needs) and Special Classes.

G Recommendation 74. Children with more severe and complex disabilities, including deafness, should be placed locally in day Special Classes attached to mainstream schools. Peripatetic support should be offered to Special Class Teachers and other staff by specialist teachers from one of the Special Schools.

***G & NGO Recommendation 75.** We recommend strongly that the Special School and ANAD along with their respective supportive Italian and Finnish NGO representatives are brought together to find a way forward in introducing Signing into the Special School(s) and developing ASL. We suggest that this process is undertaken with the support of a knowledgeable mediator, nominated by the Ministry of Education to ensure that constructive ways ahead are found.

***G & NGO Recommendation 76.** We recommend that the Government and ANAD work together to identify potential Signing interpreters and social workers for deaf people and to advance their training.

***G Recommendation 77.** We recommend that all Albanian TV stations be required as part of their licensing agreement to take account of deaf viewers and to provide increasing hours of Signed interpreted and Albanian sub-titled programmes.

***G Recommendation 78.** We would recommend that a national approach to the provision of appropriate detailed audiological testing and free supply of hearing aids to *all* deaf children (not just those in the Special School) be prioritised as a follow-on to the present broad national screening. This is likely to bridge both the Ministries of Education and of Health.

***G & NGO & D Recommendation 79.** We recommend that a new Special Education Daily Unit for autistic children be established at the Special School for Children with Special Needs in Tirana.

Recommendation 80. We recommend that a second Special Education Daily Unit should be established in the Special School for Children with Special Needs in Tirana for children with specific

language disabilities. However, this development should not start before at least two fully trained speech and language therapists become available (see Recommendation 106).

18. Educational early intervention

***G & NGO Recommendation 81.** We suggest that early intervention should be seen as a sustained high priority by Government and by NGOs for children with disabilities and especially for those of all kinds of disability at the more severe end of the spectrum

***G & NGO & LA Recommendation 82.** It is important that health, social services, education services and relevant NGOs and Associations work together to ensure that parents of children with special needs, once identified, are offered support and positive interventions for their child as early as possible. It is important that parents are supported and encouraged to love and stimulate their child and are given hope for their child's development

***G & NGO Recommendation 83.** Advice, through visiting personnel, leaflets, and the media, should be available to families from the time they are first made aware of their child's condition, if possible shortly after birth. Much could be achieved through the production and transmission of simple friendly films on public education TV channels, demonstrating parents playing and working with their children with special needs.

***G & NGO Recommendation 84.** We recommend also that the National Centre, the Department of Mental Health, ADRF's Advocacy Group and other NGOs and Disability-related Associations collaborate to develop a *range* of early intervention programmes, sharing expertise and training to try to cover the range of early intervention needs across the country. Programmes should link with existing public and private kindergartens, existing community-based inclusion projects and home-visiting programmes for older children. In some cases of missing Albanian expertise, it may be necessary to bring in qualified international professionals.

***G & NGO Recommendation 85.** In early intervention it is vitally important to encourage and empower parents and never to usurp their most important role while supporting and advising them.

19. Health services

***G Recommendation 86.** The Ministry of Health and medical training in Universities should emphasise the equal right to medical care of people with disabilities, including those in institutional care.

***G Recommendation 87.** We recommend that, wherever possible, parents of children with disabilities be given a medical 'contact person' from whom they could seek a follow-on consultation or advice.

***G Recommendation 88.** We recommend that the Ministry of Health try to alleviate the present situation of shortage of paediatricians with knowledge and interest in childhood disabilities with more training posts.

***G Recommendation 89.** We recommend that, ideally, all medication that is required for children with long-term conditions should be free. Failing this, we recommend that costs should be substantially

reduced. In the case of some life-threatening conditions with relatively small numbers of patients, financial or high quality drug donations could make a substantial contribution to remaining life.

Recommendation 90. We suggest that the Ministry of Health could prepare succinct and easily understood guidance on chargeable costs for medical services and for medicines that could be displayed in clinics, hospitals and pharmacies.

Recommendation 91. We believe that assessments of children's abilities prior to special school placement should be undertaken by developmental or educational psychologists when possible rather than psychiatrists or neurologists.

***G & LA Recommendation 92.** No person involved in the assessment of a child should describe the child as, or recommend that a child is, 'ineducable'.

***G & NGO & D Recommendation 93.** We would like to see a domiciliary paediatric nursing service developed to help families care for their dying children, and we would also like to see a suite of rooms for these children and their families being attached to the Paediatric Department of the main hospital in Tirana when home care is not possible.

***G Recommendation 94.** We recommend that the Ministry of Education provides appropriate educational and psychological services for children resident longer-term in the Mother Tereza Hospital Paediatric Department and in the Military Hospital Orthopaedic Department. This should be undertaken in consultation with both Hospitals, with the service being based in the Mother Tereza Hospital but serving both establishments.

***G & NGO & D Recommendation 95.** We recommend that an NGO and/or Donor collaborate with the Ministry of Health to ensure dental treatment of children with disabilities by:

- ❖ equipping a mobile dental unit with disabled access,
- ❖ paying for post-graduate specialist training abroad for a qualified and interested dentist,
- ❖ funding the employment of a dentist, trained dental nurse and anaesthetist, and
- ❖ covering the running costs of the Unit to undertake peripatetic dentistry across Albania for children with disabilities who have not been able to access other dental services.

20. Professional roles and training

Recommendation 96. We recommend that all initial degrees in both medicine and dentistry contain required elements of general disability awareness and of more specific implications for professional practice in working with children and adults with disabilities

***G Recommendation 97.** We recommend that the Ministry of Health, in collaboration with relevant University Faculties, encourages emerging doctors and dentists towards specialisms in childhood disability within paediatrics and in dentistry

***G Recommendation 98.** We recommend both that Social Work positions that involve intensive work with children with disabilities should be filled by graduate Social Workers and that Social Work degree courses should have a more substantial theoretical and practical in-put relating to children with disabilities

G Recommendation 99. We further recommend that in all in-puts to all professional graduate courses (in medicine, dentistry, social work and psychology), a social model of disability is presented but that a more detailed knowledge of specific conditions is subsumed within this model, and that a holistic approach to the assessment of children be adopted in training and in practice.

G & LA & NGO Recommendation 100. All workers at all levels in any establishment whether of the Ministry of Education, Ministry of Labour and Social Affairs, NGO or private, should have some basic induction training that covers issues such as disability awareness and children's rights as well as an introduction to their specific role. This training should be the responsibility of the Director. A national training package could be prepared by ADRF and the Child Rights Centre of Albania (CRCA).

G Recommendation 102. We suggest that employers should facilitate the further education and qualifications of auxiliary workers who have not fulfilled their own educational potential.

G Recommendation 103. We suggest that educators who wished to do so would have the opportunity to become Resource or Specialist Resource Teachers possibly i) by means of a short transition course for those with appropriate general educational qualifications, followed by ii) undertaking the relevant specialist course.

***G Recommendation 104.** We recommend that *all* teachers and educators undertaking initial training in any pedagogical secondary school or pedagogical or other University should receive an introduction to the inclusion of children with disabilities/special needs as an integral part of their course. The processes of differentiation and the collaborative development of IEPs should be addressed. A national package of teaching and learning materials should be developed and made available to the various training institutions to support students and lecturers who may themselves have little experience in this area.

***G Recommendation 105.** We recommend that the development of a modular course for teachers and educators working with children with disabilities in mainstream and special schools and classes be discussed by key personnel in the Ministry of Education, lecturers in pedagogy from the various Universities, Education Authority Directors for Special Needs, and Directors of schools. If approved, a research and development strategy should be planned for the programme and a potential Centre for Special Needs Teacher Development should be identified, probably within Tirana University.

***G Recommendation 106.** We recommend the setting up a full national three or four year degree course for professional physiotherapists. Some classes should be shared with medical students and (to a lesser extent) with PE students to reduce some of the costs in establishing the course. Their role should include not only specific training in working with children with all kinds of physical and complex disabilities but also a critical understanding of mobility aids.

***G & NGO & D Recommendation 107.** We suggest that two language students be identified for full professional training abroad as speech and language therapists and that they should subsequently act as advisers across other professions and be an integral part of the staff team for the proposed Special Education Unit for Children with Specific Language Disabilities.

***G & NGO & D Recommendation 108.** We recommend strongly that two individuals with substantial experience of working with deaf and with blind children be funded to train abroad in intensive short courses as a Paediatric Audiologist for deaf children and as a Mobility Training Instructor for blind children respectively.

***G Recommendation 109.** We suggest that a national Register of Professional Training for those working with children with disabilities be kept, possibly by the Albanian National Monitoring Centre

for Disability or other appropriate agency, in order to avoid overlaps and gaps in training provision and to facilitate the sharing of training.

***G & LA & NGO Recommendation 110.** Interpersonal skills training should be embedded in all professional training courses for people working or intending to work with children with disabilities and their families.

References

- Albanian Disability Rights Foundation (2003) OSAAB and ADRF: Advocates for Special Needs Babies, in *Challenge, Issue 11*. Tirana: ADRF.
- Albanian Disability Rights Foundation (Nano, V.) (2002) *Albanian Schools in the Integration Process: Study on the integration of children with disability in regular schools*. Tirana: ADRF.
- Albanian Disability Rights Foundation ADRF (1998) *The Albanian Public Opinion and Persons with Disability*. Tirana: ADRF.
- Albanian Government (2002a) *Normative Dispositions for Pre-university Education, Article 57 – The Education of Pupils with Special Needs*. Tirana: Albanian Government.
- Albanian Government (2002b) *Draft Initial and First Report of the Albanian Government CRC Committee of Geneva*. Tirana: Albanian Government.
- Booth, T. (1998) England: Inclusion and exclusion in a competitive system, in T. Booth and M. Ainscow (Eds.), *From Them to Us: An International Study of Inclusion in Education*. London: Routledge. Pps 193-225.
- Booth, T. and Ainscow, M. (Eds.) (1998) *From Them to Us: An International Study of Inclusion in Education*. London: Routledge.
- Coleridge, P. (1993) *Disability, Liberation and Development*. Oxford: Oxfam.
- Handicap International (2000) *Initiatives and Structures Existing in Albania in Disability Framework*. Tirana: Handicap International.
- Eiser, C. (1993) *Growing Up with a Chronic Disease: The Impact on Children and their Families*. London: Jessica Kingsley Publishers.
- Hastie, R. (1997) *Disabled Children in a Society at War: A Casebook from Bosnia*. Oxford: OXFAM.
- Meyer, D. and Vadasy, P. (1997) Meeting the unique concerns of brothers and sisters of children with special educational needs, in Carpenter, B. (Ed.) *Families in Context*, 62-75. London: David Fulton Publishers.
- Musai, B. (2001) *A Brief Description of the Albanian Education System and Teacher Training*. Tirana: University Institute of Pedagogy.
- O'Hanlon, C. (1993) *Special Education: Integration in Europe*. London: David Fulton.
- Red Barnet (2002) *The Regional Situation of the Institutionalised Children: Alternatives to Institutional Care*. Shkoder: Red Barnet.
- Richardson, R. and Wood, A. (2000) *Inclusive Schools, Inclusive Society: Race and Identity on the Agenda*. Stoke on Trent: Trentham Books.
- Save the Children: Albania (May 2002) *Report on the Findings from the Desk Study on Children with Disability*. Tirana: Save the Children.
- UNESCO (1996) *Survey on Special Needs Education Law*. Paris:UNESCO.
- UNESCO (1994) *The Salamanca Statement and Framework for Action*. Paris:UNESCO.
- United Nations (1989). *The Convention on the Rights of the Child*. Geneva: United Nations Children's Fund.

We were also informed by information leaflets, newsletter, reports and Annual Reports of Albanian GO s and NGOs, of, among others, the Albanian Disability Rights Foundation (ADRF), Child Development Centre (CDC), Help the Life (Ndihmoni Jeten), Bethany Christian Services, MEDPAK, Save the Children, Albanian National Monitoring Centre for Disability, National Centre for the Development and Rehabilitation of Children.

NB Appendix 1. (The research team, research methodology and organisation of the report) includes a research-specific reference list.

Appendix 1: The research team, methodology used and structure of the report

The research consultants were Alison Closs, Senior Lecturer in the School of Education, Section of Equity Studies and Special Education, University of Edinburgh, Scotland, and Virxhil Nano, Head of Qualifications Department, Institute of Pedagogical Research, Tirana, Albania. The former is a teacher/educationalist and researcher experienced in both inclusive education and in the interface between education and health services in the UK, Czech Republic, Former Yugoslavia and Oman. The latter is an educational psychologist with experience in the US, Romania and Sweden as well as in Albania. The consultants' work was extended and facilitated by Estevan Ikonomi, a qualified social worker, now Disability Programme Co-ordinator, Save the Children, Albania, who arranged and managed the research schedule and resources, and who acted as Albanian-English interpreter and translator. Bringing together different professional backgrounds, national and international practice and research/consultancy experience enabled a blending of insider knowledge and cultural sensitivity to the Albanian context with ideas drawn from wider international developments.

The research, undertaken during February 2003 and extended by the Albanian members of the team into March, was qualitative rather than quantitative. It involved undertaking a large number of visits to specialist and non-specialist Governmental (25) and Non-Governmental (11) organisations, and interviewing many parents (44), professionals (42) and a smaller number of children and young people (17) (see details in Appendix 2). In the case of specialist GOs, the sample was extensive as one or both Consultants visited all GOs except for one special school and three locations with five special classes (see Appendix 3). We have only identified GOs and NGOs individually in the report in so far as it is useful to the discussion to do so and have at no point used the names of individuals, although some will inevitably be recognisable.

In the case of parents, children and professionals, we undertook a purposeful sampling procedure identifying 'willing and informed' participants. All volunteered to speak with us and we have tried, as far as possible, to maintain confidentiality in relation to their identity and to observe ethical standards in our research (Lee 1993). They also filled a matrix of desirable variables. To have confidence that we might correctly identify critical issues, we wanted to speak with respondents who came from different geographic areas, rural and urban settings, were of different ages, levels of education/training, and socio-economic and cultural backgrounds. They were all intimately concerned with disability as an issue; children experiencing it first hand, parents through their caring and developmental role and professionals either through direct work with children with disabilities or by holding a key responsibility for a relevant organisation or service. The closeness of experience in respondents tends to add emphasis to their evidence. Thus we selected our samples purposefully, for theory driven reasons and for potential intensity of data (Miles and Huberman 1994: 29). The researchers visited all the main urban centres and some rural areas of Albania, only not reaching the far north-east and the extreme southern coast of the country.

We used a semi-structured interview procedure that took all adult and young person respondents through some of the same broad open-ended questions about their experiences and their views on the lives of children with disabilities in Albania. We identified some significant recurrent views and common issues and themes were also noted as well as views that were particular to the individual. Conversations with children were more spontaneous and conversational, attempting to set the young respondents at their ease. It was important to the research to ensure that their real views were heard clearly (Alderson 1995), on matters that are, after all, even more important to them than to the other respondents, as the UN Convention on the Rights of the Child (UNICEF 1989) asserts. This examination of experience – in this case experience of disability - from different perspectives is termed 'triangulation' (as is the process of mapping land accurately using three trigonometric points) (Robson 2002). It gives added certainty to the data and also highlights commonality and differences in perspectives both within and across groupings.

Detailed notes were taken by the main researcher, backed up by briefer notes of key points by the second researcher. The main researcher's notes were also marked to indicate points that the respondents particularly emphasised. The reports were word-processed and re-read as soon as possible after the interview – generally on the same day or the next. The reports were then analysed by reading and re-reading to identify significant recurring issues and themes (Ritchie and Spencer 1994) and later by computer scanning for key words and phrases using Nudist qualitative data analysis software. The key points were then also listed and finally re-grouped under broad headings. These broad headings then became the headings of the sections of the report, ordered so that they make a coherent narrative.

The views of the respondents and the themes and issues are linked together by the use of verbatim quotations from professionals, parents and children and by case studies of families, or institutions or projects. The quotations are used to remind readers of the reality of individual children, parents and professionals and to enrich the research narrative. People with disabilities, adults and children, and their families are all too often the recipients of advice, description and prescription from others, especially professionals. This report gives prominence to the views of parents and to children with disabilities.

The themes and issues identified also draw on salient pre-existing research and factual reports by others and official national and international documents. The UK Consultant had undertaken prior reading of these, the Albanian researcher and the team facilitator were both already familiar with much of this material and the Albanian researcher was himself the author of several relevant studies.

This type of research is also illustrative and may be used *illuminatively*. Identified themes and issues are significant and may be widespread but they will not necessarily be as described in *every* situation. They can, however, be used, as may the quotations, by service managers, policy makers and individual professionals to reflect critically on their own provision to ask themselves and their colleagues, *'Is it like this where we work? Do we do that? Would our clients say this? Are children in our area treated in this way? Could we do this? Would that help the children with whom we work? Is there any alternative and better way than what we are currently doing?'* By such reflection new solutions and constructive ways forward may be identified that are suitable for particular contexts. It is also less painful to discover the shortcomings of one's own services or provision in this self-evaluating way than to have it pointed out during inspection!

Sections in the Report are headed according to groups of the identified themes and issues, many of which are common across all or many disabilities and are in fact related more to Albanian society, its stage in development, structures and organisation than to the nature of specific disabilities. The report adopts a broadly social model of disability that suggests that, while children may have specific physical or cognitive impairments/disabilities, how far these impairments/ disabilities actually become *handicaps* depends to a considerable extent on how society adapts its systems and structures to include, or exclude, the children. It emphasises the need to alter legal, physical, emotional and social contexts so that they are inclusive.

The report, however, does take a closer look sometimes at what would help children with specific disabilities. This is *not* regressing into a 'medical' or 'deficit' model of disability. (The medical model focuses on what is wrong with a disabled child and adopts a 'remedial' approach only to the child, the perceived 'defect' and sometimes the child's family. It tends to devalue difference and to ignore societal factors) The more 'disability-specific' approach is adopted occasionally to ensure that particular needs are highlighted when necessary. More specific recommendations may also enable the reader who is either a potential Donor or NGO Organiser with a particular focus to gather some ideas for projects or donations that are based on research. The recommendations of the report are collated in Section 22.

We think that the essence of our research in relation to children with disabilities is well described in a book specifically about researching disability (Barton and Clough 1995: 143)

All the accounts provided in this book are informed by a desire to see change take place at the material, institutional, political and attitudinal levels of society; barriers to participation, equity and human rights must be challenged and changed. This involves the researcher taking the voice of disabled people seriously, listening to them, exploring their lived experience in particular contexts. Getting beneath the surface to the personal feelings and experiences of participants is a significant aspect of this research.

It is only by building up a detailed three dimensional picture, piece by piece, that some overview of the lives of children with disabilities may be obtained in such a complex context as Albania at the beginning of the 21st Century. The picture in this report will *not* be complete in every detail; it will show some very positive aspects and developments but it will also highlight many of the contradictions, confusions, overlaps and, above all, gaps in provision and systems. Those issues perceived by the researchers to be most urgent are prioritised for action by Government and its institutions and agencies, NGOs and donors, as national and international resources allow.

References

- Alderson, P. (1995) *Listening to Children: Children, Ethics and Social Research*.
- Barton, L. and Clough, P. (1995) Conclusions: many urgent voices, in P. Clough and L. Barton (Eds.) *Making Difficulties: Research and the Construction of SEN*. London: Paul Chapman.
- Lee, R. (1993) *Doing Research on Sensitive Topics*. Sage Publications, London and Thousand Oaks, Ca.
- Miles, M. and Huberman, A. (1994) *Qualitative Data Analysis*. Sage Publications, London and Thousand Oaks, Ca.
- Ritchie, J. and Spencer, L. (1994) 'Qualitative data analysis for applied policy research', in *Analyzing Qualitative Data* (Eds.) A. Bryman and R. Burgess. Routledge: London.
- Robson, C. (2002 2nd Ed.) *Real World Research*. Oxford: Blackwell.
- United Nations (1989). *The Convention on the Rights of the Child*. Geneva: United Nations Children's Fund.

Appendix 2: List of meetings held and visits made by the Research Team for discussions with Key Respondents

Government Organisations (GOs):

(These visits normally included extensive discussions with key representatives of the organisations – the Director in all but two organisations - and in some cases included several key professionals: however, only one representative is counted for each)

Special schools *(including residential schools for deaf and for blind children and young people)* 7

'Inclusive' basic education schools 2
(8-year local schools that include children with disabilities in mainstream and/or special classes)

Residential Development Centres 6

Day Centres 5

Other Governmental Organisations 4
(These were two children's development centres focussing respectively on mental health and on physical development/rehabilitation [Ministry of Health], an agency for statistics and quality assurance [Ministry of Labour and Social Affairs] and a University Department of Pedagogy)

Hospitals (Paediatric Dept.) *(This visit was informal and brief, undertaken on the way to meet key medical specialists.)* 1

Total number of GOs visited or / representatives met 25

Non-Governmental Organisations working with children with disabilities (NGOs) (NOT including parent groups):

(These involved extensive discussions with the head/senior local representatives of the organisations)

International NGOs 5
(These comprised two Centres working primarily with children/young people with mental disabilities, one orphanage/adoption organisation, UNICEF, and an organisation concerned with the material and professional development of day and residential GOs)

Albanian NGOs 6

(Organisations working generically with disability across all ages (including advocacy by disabled people), with mental disabilities and organisations of people with sensory disabilities. One NGO arranged for the Research Team to meet with its local representatives in two areas and with a group of nine professionals associated with the NGO as volunteers. In several other NGOs more than one representative was involved in the meetings: however, only one representative is counted for each in the total given below.)

Total number of NGOs visited or representatives met 11

Individual professional people (other than GO and NGO representatives) 6

(These included senior officials of the Ministries of Labour and Social Security and of the Ministry of Education, three senior medical specialists [psychiatry / neurology, oncology and cystic fibrosis, respectively], and one general paediatric specialist who is the medical referee on the national [central] Social Benefits Tribunal [KEMP].)

Total number of professionals met from GOs and NGOs (counting only one from each) and Individuals 42

Parents: 24

3 Parent mutual support groups

(These groups were all concerned with children with moderate to severe/profound/ complex mental disabilities, sometimes combined with physical and/or sensory disabilities, and comprised respectively 8, 7 and 9 parents at the Team's meetings.)

Individual parents or small informal groups of 2 or 3 parents (we have counted 2 parents from I family as 1) 20

(These included 13 meetings with individual parents or families [9 of them within their own family homes] and two meetings with small groups [3 and 4 parents respectively]. Their children had mental disabilities, physical disabilities, profound and complex disabilities, blindness and deafness. They included one 'Egyptian' and one Roma parent.)

Total number of parents met 44

Children and Young people 8

Children/young people of school age (up to age 17)

(These meetings were individual except for one brief meeting with three pupils with mental disabilities in the presence of their teacher. The other children/young people had physical disabilities)

(1 – this child had not been able to attend school), were blind (2) or deaf (2). The two blind pupils had residual usable sight, one deaf pupil could use only sign/finger spelling while the other used both oral communication and sign/finger spelling. The children/young people ranged in age from 14 to 17.)

Young adults beyond school age

9

(Three of these meetings were individual [one young adult with combined mild learning difficulties, physical and genetic disabilities – this young person had not been able to attend school, and two young adults with physical disabilities and normal cognitive abilities who had not been enabled to complete their education.] Two deaf young adults spoke within the context of a wider discussion in an association for deaf people. Four young people with mental disabilities spoke briefly within a meeting of parents and young people.)

Total number children/young people met

17

Appendix 3: Table of number & location of Residential Institutions, Day Centres Special Schools & Special Classes with number of Residents, Clients & Pupils

Area City/Town	Residential Developmental Institutions	Day Centres	Special Schools (SN = Special Needs)	Special Needs Classes
Tirana	1 36 (Mon-Fri)	1 30	1 SN 86 1 Deaf 160 1 Blind 67	

Mid Albania (out of Tirana)

Durres	1 35	1 15	*1 SN 92	
Berat	1 38			
Pogradec				*1 19
Elbasan			1 SN 76	
Lac				*1 15
Fier				*3 18
Librazhd				2 20

N Albania

Shkoder	❖ 65 (including 2 Casa Famiglia Houses)	1 35	1 SN 96	
Lezhe		1 38		

S Albania

Vlore	1 17		1 SN 96	
Korca	1 44	1 25	1 SN 49	
TOTALs	6 235	5 113	8 722	7 72

*Asterisked locations were the only institutions **not** visited by the research team. Figures given above at the Institutions visited were accurate at the time of the visit (February 2003) and remaining figures were checked with the Ministry of Labour and Social Affairs and the Ministry of Education

Numbers of Children with Disabilities in Albanian State Orphanages

N.B. This table is taken from the Report *The Regional Situation of the Institutionalised Children* (Red Barnet 2002). Some of their statistics predate the report. This table is therefore currently only an estimate. Numbers may have dropped with the opening of the Residential Developmental Centre in Vlora but the current populations in Centres of all kinds are under review. *It is also important to note that numbers of children with disabilities within private/NGO orphanages are **NOT** included.*

Social Welfare Institutions	Total number of children	Number and (%) of children with disabilities
4 Institutions for 0-3 yrs	139	21 (15%)
Institutions for 3-6 yrs	57	12 (21%)
Tirana 6-14	100	21 (21%)
Shkoder 6-14	99	25 (25%)
Saranda 6-14	58	0 (0%)
Total	453	79 (17%)

Appendix 4: Questionnaire for NGOs working with children with disabilities in Albania

Details of specific projects are requested (over). If your NGO has undertaken several projects, please make as many copies of the back sheet of this proforma as required.

Please return to Estevan Ikonomi, Save the Children, Tirana, and thank you for your help!

1. Name of NGO _____

2. Is it local or International? If local, was/is it linked to any International NGO?

3. Address, telephone number, fax and email address of office

4. Name of current local director/representative in charge of NGO

5. Name and position of person completing questionnaire if other than person above

6. Number of years & months work of your NGO in Albania to date:

7. Geographic area/Town in which NGO works _____

8. Are you or your key workers aware of any critical gaps in any kind of provision or services (not just your own) for children with disabilities? (please list these, if possible, in order of priority)? _____

PROJECTS:

Projects/work currently being undertaken currently or in the *recent* past with, or in relation to, children with disabilities and/or their families: (If leaflets are available giving the relevant information in English, these may be used instead, *augmented with notes if necessary.*)

1. Title, aims and brief description of **Project 1**, including nature of provision made or services provided

2. Town/geographic area of work location_____

3. Source of funding_____

4. Start and actual/probable finish dates of project_____

5. Number & age group/s of children/families involved and any other selection criteria for involvement

6. Number of workers involved:

a) qualified and paid (specify qualification)_____

b) unqualified and paid_____ c) volunteer_____

d) local/international_____/_____
e) disabled employees_____

7. Key achievements of project:_____

8. Problems encountered in the project:_____

9. Has any follow-up work been undertaken or planned for the future (If so, please specify what)

Appendix 5: List of Acronyms (English Language)

<i>Acronym</i>	<i>Full name / term</i>
AABP	Albanian Association of Blind People
ADRF	Albanian Disability Rights Foundation
ANAD	Albanian National Association of the Deaf
ASAAB	Association for the Support of Albania's Abandoned Babies
ASED	Association for the Support of Children in Distress (Association pour le Soutien d'Enfance en Detresse)
CRC	(UN) Convention on the Rights of the Child
CRCA	Children's Rights Centre Albania
EC	European Community
GO	Governmental Organisation
KMCAP (previously KEMP)	Medical Commission for Determining the Ability to Work (previously Commission of Medical Examination for Work)
MEDPAK	(Mbrojta E te Dretjave te Personave me Aftesi te Kufizuara [Albanian]) Protection of the Rights of Persons with Disabilities
NGO	Non-Governmental Organisation
NMCD	National Monitoring Centre for Disability (also known as the National Observatory of Handicap)
UNESCO	United Nations Economic, Social and Cultural Organisation
UNICEF	United Nations International Children's Emergency Fund